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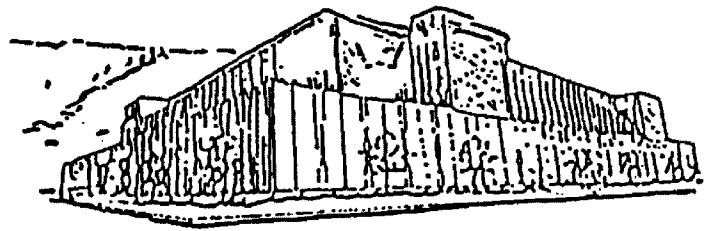
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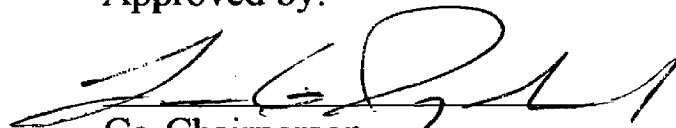
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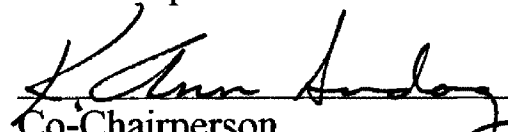
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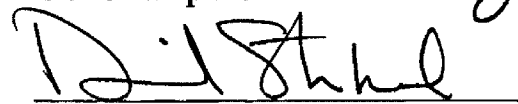
Presented in partial fulfillment of the requirements  
for the degree of  
Master of Science

Department of Health and Human Performance  
School of Education Graduate School  
The University of Montana  
Missoula, Montana  
May 15, 1998

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## **Thesis Abstract**

Landry, Sarah Elizabeth, M.S., May 1998

Health and Human Performance

**An Assessment of HIV Prevention Needs among Montana's Native Americans on the Flathead Indian Reservation in Montana**

Committee Co-Chairs: K. Ann Sondag, Ph.D. *KAS*  
L.G. Dybdal, Ph.D. *LG*

The purpose of this study was to assess the HIV prevention needs of Native Americans on the Flathead Indian Reservation in Montana. This information will be used to develop a social marketing campaign designed to increase perceptions of behavioral risk of HIV infection and decrease barriers to HIV counseling among this population. In an attempt to gain insight into Montana's Native American's experiences and perceptions regarding HIV/AIDS education and prevention services on the Flathead reservation, this investigation utilized a qualitative method of research. Data were collected through the use of focus group interviews. Four focus groups were conducted. Participants included Native American health educators in the State of Montana, members of the Indian Teacher/Parent Council, inmates at the Tribal Jail, and students enrolled at The Two Eagle River School.

Collected data consisted of notes taken (by the researcher) during and immediately following the focus groups as well as transcribed audiotapes of the focus groups interviews. For the purpose of this study, a qualitative transcript-based content analysis was utilized. Qualitative transcript-based content analysis involves examining the collected data manually in order to find reoccurring themes. Focus groups were analyzed for themes within each group and across groups. Major themes common across focus groups included the following: 1) the problem of HIV/AIDS misinformation on the reservation, 2) the need for more HIV/AIDS education and information for both Native adults and Native youth, and 3) a lack of perception regarding HIV/AIDS infection risk. Recommendations for development of a social marketing campaign among Native Americans are discussed based on thematic results of focus group interviews. Recommendations include strategies targeted specifically towards Native adults and strategies targeted specifically toward Native youth. Strategies have the potential to be instrumental in addressing several of the problems Native adults and Native youth perceived as detrimental to the Native community.

## **Acknowledgements**

**...I have seen that in any great undertaking it is not enough for a man (or woman) to depend simply upon himself (or herself).**

**-“The Education of Little Tree”  
Forrest Carter**

My deepest heartfelt thanks to Dr. Laura Dybdal and Dr. Annie Sondag, who repeatedly went far above and beyond the duties of thesis chair's. I am forever grateful to you both for your help and support not only throughout this endeavor but also throughout my years at The University of Montana. I couldn't have done it without you two. Your wisdom, your humor, your stories and your friendship I will never ever forget. What you both have done for me-academically and personally-cannot be expressed in words. Thank you so very much.

To my parents, who have, by example, taught me the value of education, hard work and perseverance. Nothing seems insurmountable when I have you two. I love you both dearly.

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# **CHAPTER I**

## **Introduction to the Study**

Acquired Immunodeficiency Syndrome (AIDS) was first reported in 1981. In the following years, scientists learned AIDS is caused by a deadly virus, the virus is transmitted in specific ways, and more importantly, becoming infected with the virus can be prevented. The virus, Human Immunodeficiency Virus (HIV), damages the immune system and eventually cripples the body's ability to fight the disease, resulting in death (Allensworth, Gayle, & Kerr, 1991).

The AIDS epidemic has been monitored by the Centers for Disease Control and Prevention (CDC) since the first reports of infection. As of June 31, 1997, 612,078 cases of AIDS had been reported to CDC by state and local health departments: 604,176 adults/adolescents and 7,902 children under 13 years of age. It is now the leading cause of death among Americans between the ages of 25 and 44. Through 1997, more than 232,000 persons were living with AIDS (American Association for World Health [AAWH], 1998). However, this cumulative number of persons living with AIDS underrepresents the number of living persons who have been infected with HIV disease because most infected persons have not yet progressed to AIDS, and many persons infected with HIV have not been tested or diagnosed. CDC (1997) estimates there currently are approximately 650,000 to 900,000 Americans infected with HIV.

HIV/AIDS has touched every community around the world, spreading to all inhabited continents. The World Health Organization (WHO) reports that while public health initiatives have achieved perceptible progress in the eradication, elimination and control of many infectious diseases within the past 20 years, HIV/AIDS is an exception.

Due to its ever-changing character and the complex role of factors that determine the progression from HIV infection to full-blown AIDS, the challenge of overcoming the disease remains a pressing issue for global and national leaders everywhere (CDC AIDS Prevention Guide, 1997).

In the United States, the HIV/AIDS epidemic has spread and its demographics have shifted. The disease that once heavily infected and affected the Caucasian men-who-have-sex-with-men population has spread to all racial and ethnic groups in the United States. HIV/AIDS knows no demographic boundaries. It does not discriminate against sexual orientation, nor against age, gender, race, culture, or demographics. HIV affects homosexuals and heterosexuals, young and old, men and women, black and white, native and non-native, as well as city dwellers and country folk. No category of people or their location is exempt (Rathus & Boughn, 1993). Even the most rural states, such as Montana, have infected individuals. In fact, rural populations have the highest rates of increase in AIDS cases, representing 6.7 percent of all cases in the United States in 1996, with heterosexual contact accounting for most cases in many areas (AAWH, 1997). As the epidemic spreads to new populations, prevention programs must respond to new needs and perceptions with new ways of communicating, new messages, and a new understanding.

AIDS is not only spreading to new populations, but it is also increasing significantly among women, various racial/ethnic groups, injection drug users and through heterosexual contact. As there is no national standard for reporting of race/ethnicity in AIDS/HIV surveillance, AIDS/HIV cases among Native Americans, Alaskan Natives and Native Hawaiians are thought to be undercounted. Accurate reporting is an ongoing challenge

for these populations due to racial/ethnic misclassification (AAWH, 1997). Furthermore, this becomes an even bigger challenge as the onset of new drugs and improved medical care reduces the incidence of AIDS but not HIV.

In the last 500 years, large segments of the Native American population have been wiped out as a result of viral infections and AIDS holds a similarly devastating potential (Harris, 1997). Some reservation health educators compare AIDS with previous killing epidemics, such as cholera, small pox, and tuberculosis (Sowers, 1995). They believe the CDC numbers do not accurately reflect the AIDS epidemic in the Native American population. Under reporting is one cause of these inaccuracies. For some tribes, AIDS is taboo and infected members are ostracized. Thus, fearing isolation, infected members may not identify themselves (Reeves, 1996).

Currently, the number and scope of published intervention studies in the health education literature that include Native Americans are limited. However, results from a study conducted at The University of Montana in 1997 concluded that Montana's Native Americans believed themselves to be at "low or no risk" for contracting HIV/AIDS (Mochi, 1997). Additionally, many Native Americans reported the following barriers to HIV testing: usually practice safe sex; fear of people finding out; mistrust of the public health department; and unsure of where to get tested. Study results suggest that it is imperative for governmental health agencies and other interested parties to increase perceptions of risk among Montana's Native Americans and to decrease barriers surrounding HIV counseling and testing. With a cure remaining elusive, prevention is the only method to restrain the rising rates of infection.

Native Americans suffer from exceptionally high rates of acute and chronic disorders caused by high-risk behaviors, therefore, health education interventions that prevent disease and promote preventative health behaviors are particularly important. Unfortunately, there are few published health intervention studies that target Native Americans. Much more effort is needed to provide Montana's Native Americans with effective and culturally sensitive health education interventions to improve health behaviors and overall health status (LeMaster & Connell, 1994).

Controlling HIV infection, especially among Montana's Native American communities, requires effective and multi-faceted prevention strategies. Nationwide, countless community-based organizations, AIDS service organizations, faith-based ministries, state and local health departments, and federal agencies are using various aspects of social marketing in HIV and sexually transmitted disease (STD) prevention programs (Odgen, Shepherd, & Smith, 1996). Social marketing is the concept of using traditional marketing tools to "sell" health behaviors to target audiences. The goal is to promote behavior that is socially desirable and contains clearly defined values for the individual and the community, such as HIV prevention. A particular behavior (such as condom use) is made socially desirable by linking it to something that is valued by the targeted community. It is a process for developing programs that create, build and maintain beneficial exchange relationships with a specific audience segment for the purpose of influencing behaviors in the interests of the individual and society (HIV Capsule Report, 1994).

Facilitators of social marketing use epidemiological and demographic data - combined with information about possible audiences gleaned through focus groups,

individual interviews, and other means, to define priority groups and their needs and to guide decisions about interventions. What social marketing offers is a new perspective and a systematic way to design, deliver, and evaluate prevention programs that are focused on a targeted audience and its behavioral goals. This approach has been proven successful. Programs have had major impacts and campaigns have been improved. More importantly, behaviors have been changed (Odgen et al., 1996). Social marketing can motivate people to take action. It is an effective tool that will not only convey vital prevention information to Montana's Native Americans, but also, ultimately curb the rising death toll.

### **Statement of the Problem**

HIV/AIDS is increasing significantly among various racial/ethnic groups (CDC, 1997). In addition, a recent study conducted at The University of Montana in 1997 concluded that Montana's Native Americans believed themselves to be at "low or no risk" for contracting HIV (Mochi, 1997). This perception may be one barrier that prevents Montana's Native Americans from seeking HIV testing and counseling. It is imperative to increase perceptions of HIV-risk among Montana's Native American population and decrease barriers surrounding HIV counseling and testing. The first step in accomplishing this goal was to gather information regarding HIV prevention needs from the Native American community. Information from this study will be used to design relevant, effective and culturally sensitive HIV education strategies that meet the needs identified by the Native people.

### **Purpose of the Study**

The purpose of this study was to assess the HIV prevention needs of Native Americans on the Flathead Indian Reservation in Montana. Subsequently, this information will be used to develop a social marketing campaign designed to increase perceptions of behavioral risk of HIV infection and decrease barriers to HIV counseling and testing in that population.

### **Research Questions**

1. What are the needs of Montana's Native Americans regarding HIV/AIDS prevention?
2. What are the most effective strategies to increase awareness and perceptions of risk of HIV infection among Montana's Native American population?

## **Need for the Study**

Before health education programs can be planned and implemented for a certain group, it is vital to assess the needs of that group. Too often interventions are implemented prematurely without development of an understanding of the target population. Understanding the target population and their experiences requires that an investigator take into account relevant context in its natural state. It is important to understand the reality of the population, from the perspective of the participants before a health program can be planned or implemented to modify their behaviors (Emery, Ritter-Randolph, Strozier, & McDermott, 1993). To date, there have been no assessments of the HIV/AIDS education needs of Montana's Native Americans, separate from other populations. Therefore, to plan and implement an HIV/AIDS prevention program in Montana's Native American population, the needs of this population must first be assessed and examined.

## **Significance of the Study**

Information from this study will provide the Public Health Department, the Native American Advisory Committee (NAAC), and members of the Native American population with an understanding of the HIV/AIDS prevention needs of Montana's Native American population. Results from this study will be used to develop a social marketing campaign for the Flathead Indian Reservation. This campaign has the potential to: 1) increase Native Americans' awareness of risky behaviors associated with HIV infection, 2) increase the number of Native Americans who participate in counseling and testing by reducing the barriers to HIV counseling and testing, and 3) ultimately, reduce the number of Montana's Native Americans who become infected with HIV.



## **Assumptions**

Several assumptions were made while collecting data for this investigation. The following is a list of these assumptions:

- 1.) Focus group interview participants fully understood the questions before they responded.
- 2.) Focus group interview participants answered honestly and reported accurately from past experiences.

## **Limitations**

It is reasonable to acknowledge that limits exist within any study. The following are possible limitations that may exist within this study:

- 1.) The study was limited to data gathered during focus group interviews.
- 2.) Focus groups were conducted by Native Americans, however, the presence of non-Native Americans may have inhibited participant disclosure.
- 3.) Focus group participants were limited to contacts' affiliations.
- 4.) During the focus groups, participants were limited by their memory of previous experiences or what they were willing and able to share.
- 5.) Due to the sensitive nature of the questions and potential stigmatism, responses may have been inaccurate.
- 6.) Analysis and interpretation of the data is value-laden and therefore may have been influenced by the researcher's personal attitudes, biases and perceptions.

## **Delimitations**

The following are possible delimitations or boundaries that were considered for this study:

- 1.) The study was delimited to Native Americans on the Flathead Reservation in Montana.
- 2.) The participants were delimited to Native Americans on the Flathead Reservation in Montana who volunteered to participate in focus group discussions.
- 3.) Data were collected via focus groups.
- 4.) Data were restricted to self-report of respondents.

## Glossary

**AIDS:** Acquired Immunodeficiency Syndrome; characterized by the severe HIV (Human Immunodeficiency Virus) related immunosuppression and associated conditions which include life threatening illnesses (NASTAD Social Marketing Update, 1997).

**Counseling and Testing (CT):** “Refers to the voluntary process of client-centered, interactive information sharing in which an individual is made aware of the basic information about HIV/AIDS, testing procedures, how to prevent the transmission and acquisition of HIV infection, and given tailored support on how to adapt this information to their life.” (Academy for Educational Development [AED], 1995, p.3).

**Epidemiology:** The study of the patterns and determinants of health and disease in populations (Odgen et al., 1996).

**Focus Group:** A group of people assembled to discuss a defined topic under the direction of a moderator who promotes interaction and assures that the discussion remains on the topic of interest (Stewart & Shamdasani, 1990).

**Health Promotion:** Health promotion seeks to develop community and individual values that can help maintain and enhance the state of well-being. The report of the Department of Health Education, and Wellness Task Force on Prevention (USDHEW, 1978) defines health promotion in terms of wellness and lifestyle programs.

**Health Risk Behavior:** Any personal activity that places an individual at risk for poor health and contributes to a higher probability of morbidity and mortality (CDC, 1995).

**HIV:** Human Immunodeficiency Virus, the causative agent of AIDS. An individual may be infected with HIV for several years before developing any of the symptoms or conditions associated with an AIDS diagnosis. That is, a person may be HIV-infected (or HIV-positive), but not have AIDS (NASTAD Social Marketing Update, 1997).

**Incidence:** “The number of new cases of a disease that occur in a defined population within a specified time period” (Schochetman & George, 1994, p.394).

**Prevalence:** “The total number of cases of a disease in existence at a specific time and within a well defined area; the percentage of a population affected by a particular disease at a given time” (Schochetman & George, 1994, p.396).

**Qualitative Method:** Research techniques employed to capture an understanding of a culture using the participants experiences and point of view. Techniques may include focus group interviewing and personal interviewing (Denzin & Lincoln, 1994).

**Social Marketing:** The concept of using traditional marketing tools to sell consumer products, to “sell” health behaviors to target audiences; it takes the lessons and tools from commercial marketing and uses them for behavior change (Odgen et al., 1996).

**Theoretical Saturation:** When newly gathered findings essentially replicate earlier ones (Borg, Gall, & Gall, 1996).

**Unsafe Sex:** Sexual contact with HIV-positive individuals and/or with intravenous drug users who share needles; multiple sexual partners; and avoiding protection, such as latex condoms and spermicide (Rathus & Boughn, 1993).

## **CHAPTER II**

### **Review of Literature**

The purpose of this study was to assess the HIV prevention needs of Native Americans on the Flathead Indian Reservation in Montana. Subsequently, this information will be used to develop a social marketing campaign designed to increase perceptions of behavioral risk of HIV infection and decrease barriers to HIV counseling and testing among this population. This chapter reviews and discusses current literature pertinent to the study purpose. It is divided into four sections: 1.) AIDS, 2.) Native Americans and AIDS, 3.) Social Marketing, and 4.) Focus Group Interviews.

#### **AIDS**

Acquired Immunodeficiency Syndrome (AIDS) was first reported in 1981. Within three years, scientists learned: 1.) that AIDS is caused by a deadly virus, 2.) that the virus is transmitted in specific ways, and 3.) more importantly, that becoming infected with the virus can be prevented (Allensworth et al., 1991). The virus, Human Immunodeficiency Virus (HIV), damages the immune system and eventually cripples the body's ability to fight disease, resulting in death.

Since its identification in 1981, AIDS has killed over 340,000 individuals in the United States. In fact, it remains the leading cause of death among Americans between the ages of 25 and 44 (CDC, 1996). AIDS cases are increasingly significantly among women, various racial/ethnic groups, injection drug users and through heterosexual contact. Each year, between 40,000 and 60,000 Americans become newly infected with HIV. Furthermore, the number of those *living* with AIDS continues to increase, with

estimates of more than 215,000 persons now diagnosed with full-blown AIDS (CDC, 1996). These numbers are thought to underrepresent actual cases, since most HIV-infected persons have not yet progressed to AIDS and many with HIV have not been tested or diagnosed (AAWH, 1997).

Globally, the outlook is even worse. The World Health Organization (WHO) estimates that more than 29.4 million HIV infections and 8.4 million AIDS cases have occurred world wide since the pandemic began. WHO also estimates this number will exponentially increase by the year 2000 (Rathus & Boughn, 1993). Because of its ever-changing character and the complex role of factors that determine the progression from HIV infection to full-blown AIDS, the challenge of overcoming the disease remains a pressing issue for global and national leaders everywhere (CDC AIDS Prevention Guide, 1997).

Accurate information about AIDS/HIV is critical to halting its spread. In the epidemic's early days, most prevention programs focused on giving people the facts about AIDS and HIV-what the disease is, how its spread, and what people can do to keep themselves safe (Odgen et al., 1996). Today, however, information is not enough. Most individuals already know the basic facts about HIV and its transmission. People need more than just the facts-they need support in changing behaviors that put them at risk. As the epidemic spreads to new populations, prevention programs must respond to new needs and perceptions with new ways of communicating, new messages, and a new understanding (Odgen et al., 1996).

## **Native Americans and AIDS**

Among Native Americans, there is “an increase in the prevalence of diseases and conditions with a strong behavioral component as the leading cause of mortality and morbidity” (LeMaster & Connell, 1994). In 1985, CDC reported 13 AIDS cases among the United States’ two million Native Americans. Ten years later, Native Americans AIDS cases soared to 1,569; a 9000 percent increase and a growth rate that more than doubles all other ethnic groups (Sowers, 1995). In addition, CDC (1995) reported 200 AIDS deaths in the Native American population. With increasing intravenous drug use on reservations, AIDS continues to multiply (Selik, Castro, & Pappaioanou, 1988).

In the last 500 years, large segments of the Native American population have been wiped out as a result of viral infections and AIDS holds a similarly devastating potential (Harris, 1997). Some reservation health educators compare AIDS with previous killing epidemics, such as cholera, small pox, and tuberculosis (Sowers, 1995). They believe the CDC numbers do not accurately reflect the AIDS epidemic in the Native American population. Under reporting is one cause of these inaccuracies. For some tribes, AIDS is taboo and infected members are ostracized. Thus, fearing isolation, infected members may not identify themselves (Reeves, 1996).

Results from a study conducted at The University of Montana in 1997 concluded that Native Americans believed themselves to be at “low or no risk” for contracting HIV/AIDS (Mochi, 1997). Additionally, many Native Americans reported the following barriers to HIV testing: usually practice safe sex; fear of people finding out; mistrust of the public health department; and unsure of where to get tested. Study results suggest that it is imperative for governmental health agencies and other interested parties to increase



perceptions of risk among Montana's Native Americans and to decrease barriers surrounding HIV counseling and testing. With a cure remaining elusive, prevention is the only method to curb the rising rates of infection.

As of December 31, 1997, Montana has reported a cumulative total of 376 individuals diagnosed with AIDS as defined by the CDC (1997). 215 of the 376 reported have died as a result of the illness (CDC, 1997). AIDS case reports do not reflect individuals infected with HIV who have yet to develop symptoms meeting the CDC case definition. Department of Public Health and Human Services (DPHHS) estimates that as many as 500 Montanans, including approximately 150 individuals living with an AIDS diagnosis, may be infected. Furthermore, 25 cases of AIDS has been reported to the DPHHS (1997) since 1985 in Montana's Lake County alone.

The disease patterns of Native Americans have followed a number of trends, including a shift from acute, infectious diseases to those of a more chronic and degenerative nature and an increase in the prevalence of diseases and conditions with a strong behavioral component as leading causes of mortality and morbidity. In light of these trends, health education efforts that emphasize the importance of health behaviors and the self-management of chronic diseases and conditions are especially warranted (LeMaster & Connell, 1994).

Unfortunately, relatively few intervention studies that have been designed, implemented, and evaluated by and among Native Americans have been published in the health education literature. Because Native Americans represent a sizable and growing minority group, public health approaches are needed to address the unique issues that affect their health. Intervention strategies need to be culturally relevant and sensitive to

the intended target population because of the important role that culture plays in shaping health-related attitudes and behaviors (LeMaster & Connell, 1994).

Currently, the number and scope of published intervention studies in the health education literature that include Native Americans are limited. In fact, no interventions designed to address several major health behaviors (e.g., unprotected sex, smoking cessation among adults) and chronic illnesses (e.g., AIDS prevention, tuberculosis) were identified. Several barriers contribute to the limited number of relevant studies, including: (a) the potential for mistrust among Native Americans of interventions implemented by individuals of a different cultural background, especially considering the history of non-Native researchers conducting research “on” rather than “with” the Native community; (b) language barriers, given that only traditional languages are spoken by some members of some tribes, and the low literacy in English for some Native Americans; and (c) geographic location, with the needs of Native Americans typically underserved in both rural and urban settings (LeMaster & Connell, 1994). It is very likely, however, that many health education interventions are conducted by and for Native Americans, but results are not disseminated in the published literature. Efforts to increase collaboration between researchers and staff of Native Americans service delivery and public health agencies may result in important contributions to the published literature. Much more effort is needed to provide Native Americans with effective and culturally sensitive health education interventions to improve health behaviors and overall health status (LeMaster & Connell, 1994).

## **Social Marketing**

Social marketing is the concept of using traditional marketing tools to sell consumer products, to “sell” health behaviors to target audiences. The goal is to promote behavior which is socially desirable and that contains clearly defined values for the individual and the community, such as smoking cessation, HIV prevention, or childhood immunization (Odgen et. al., 1996). A particular behavior (such as condom use) is made socially desirable by linking it to something that is valued by the targeted community (such as family values). It is a process for developing programs that create, build, and maintain beneficial exchange relationships with a specific audience segment for the purpose of influencing behaviors in the interests of the individual and society. This approach has been proven successful (NASTAD Social Marketing Update, 1997). Campaigns have been improved. Behaviors have been changed. Programs have had major impacts. Because of its compelling logic and its impressive track record, social marketing is now being used and promoted by such diverse agencies as the U.S. Agency of International Development, the Centers for Disease Control, the National High Blood Pressure Education Program, and the National Cancer Institute. It is the basis of the intervention approaches of such major consultants as the Academy for Educational Development, Family Health International, The Futures Group, and Prospect Associates. Programs as diverse as the U.S. Environmental Protection Agency, the American Cancer Society, the National Easter Seals Society, and the U.S. Department of Agriculture want to learn more about it. The acceptance of social marketing has advanced to the point where consulting organizations now have directors of social marketing (Anderson, 1995).

Social marketing applies many of the tools of private-sector marketing-primarily, intensive audience research to guide program development and delivery. Instead of selling a product, such as a car or laundry detergent, a social marketing based program “sells” behaviors that benefit both the individual and society (HIV Capsule Report, 1994). Over the past 40 years, social marketing interventions to discourage smoking, promote seatbelt use, and prevent heart disease have shown that tailored messages delivered through credible channels and bolstered by appropriate support services can change people’s health behaviors (Odgen et al., 1996).

One of the Centers for Disease Control and Prevention’s top priorities is preventing HIV transmission among people 25 and younger because this group now accounts for half of all new HIV infections (Odgen et al., 1996). Nationwide, countless community-based organizations, AIDS service organizations, faith-based AIDS ministries, state and local health education departments, other federal agencies, and national organizations share this goal. Some are already using various aspects of social marketing in HIV and sexually transmitted disease (STD) prevention programs, drug use prevention programs, and other public health efforts. Many HIV Prevention Community Planning Groups, in particular, have used key elements of social marketing in developing their plans. They have used epidemiological and demographic data-combined with information about possible audiences gleaned through focus groups, individual interviews, and other means, to define priority groups and their needs and to guide decisions about interventions. What social marketing offers these groups and others is a new perspective and a systematic way to design, deliver, and evaluate prevention programs that are focused on behavioral goals (Odgen et al., 1996).

Social marketing's successes are the result of much more than just mass media, public service announcements, or advertising campaigns. Social marketing has three key features:

- 1.) thoroughly understanding how and why "consumer segments" (target audiences) behave as they do;
- 2.) creating beneficial exchange relationships (exchanging an unhealthy behavior for a healthy one to get some perceived benefit) to influence those behaviors; and
- 3.) strategically managing prevention programs by continuously monitoring and altering interventions as needed to stay relevant to targeted audiences (NASTAD Social Marketing Update, 1996).

Social marketing campaigns have several unique aspects that distinguish them from other health information and education programs. They ask, instead of tell, people to do something in exchange for some benefit (like feeling good about protecting themselves and their partners from HIV). Social marketing programs target specific segments of the population with shared characteristics, attitudes, values and behaviors. It studies what influences and motivates behaviors among groups of people, then designs strategies to affect those behaviors - to promote, change, or maintain them. The effectiveness of social marketing campaigns is dependent on voluntary actions on the part of the target population and does not rely on regulations and laws or measure success simply by increased knowledge (HIV Capsule Report, 1994).

In retrospect, the social marketing strategy is effective for those who need new information to change behavior, as well as for those who want to change their behavior but have not. It can motivate people to take action. Social marketing is especially helpful in conveying information to those individuals who are difficult to reach through traditional prevention channels, such as Native Americans.

## **Focus Group Interviews**

Historically, quantitative research methods have predominated within the field of health education (Green & Lewis, 1986). Recently, however, the use of qualitative methods has gained increasing acceptance (Steckler, 1989). The purpose of qualitative research is to develop an understanding of individuals in their natural state, taking into account the relevant context (Borg. et al., 1996). Focus group interviews, one technique of qualitative research, can be used as an effective method for identifying attitudes and behaviors of a population with regard to specific health topics (Keller, Sliepcevich, Vitello, Lacey, & Wright, 1987). The focus group was originally developed for business marketing to gather information quickly about the attitudes, beliefs, preferences and other characteristics that influence purchasing decisions. Focus groups are now widely used to gather information for social marketing campaigns as well as for other research purposes (Krueger, 1994).

A focus group interview is an interview with a small group of people on a specific topic. Groups are typically six to eight people who participate in the interview for one-half to two hours. The participants are usually a relatively homogenous group of people who are asked to reflect on the questions asked by the interviewer. Participants hear each other's responses and make additional comments beyond their own original responses as they hear what other people have to say. It is not necessary for the group to reach any kind of consensus. Nor is it necessary for people to disagree. The object is to get high-quality data in a social context where people can consider their own views in the context of the views of others (Patton, 1987).

Focus groups, when conducted carefully and used appropriately, promise to provide a rich, effective new way of gathering qualitative evaluation information (Patton, 1987). They provide an attractive alternative to other research techniques, such as surveys or personal interviews; they can be completed quickly and inexpensively with the comfort of participating with others (Keller et al., 1987). Typically, participants react to what others in the group say; this allows the researcher to observe interesting interactions that may not occur in a structured one-on-one approach. A focus group format allows the researcher to reach several participants at one time, thereby saving valuable research time. Finally, focus groups tend to be highly enjoyable to participants (Patton, 1987).

A disadvantage to using focus groups is that the participants may be peculiar in some way, that is not highly representative of the larger group under study, so the information gathered from them may mislead the researchers. Also, the groups are not usually randomly selected and are too small to allow investigators to make broad inferences from their findings to the population (Keller et al., 1987). This weakness is overcome by conducting several focus groups and comparing the results; if findings vary dramatically in one of the groups, the information gathered from that group can either be dropped from consideration, or additional research can be done to substantiate the information (Emery et al., 1993).

When using the focus group as a qualitative research instrument, the validity and reliability of the data should be subject to scrutiny. If the data are valid, they closely reflect the world being described. If the data are reliable, two researchers studying the same arena will have similar interview results (Rubin & Rubin, 1995). Most indicators for validity and reliability do not fit within the qualitative paradigm. Lincoln and Guba (1985)

argue that for a new vocabulary and desire a search for substitute terms for “validity and reliability.” Ferrarotti (1981) is critical of the objectivity that underlies these two terms. He believes the most profound knowledge can be gained only by the deepest subjectivity between researchers and that which they are studying.



## **CHAPTER III**

### **Methodology**

The purpose of this study was to assess the HIV prevention needs of Native Americans on the Flathead Indian Reservation in Montana. Subsequently, this information will be used to develop a social marketing campaign designed to increase perceptions of behavioral risk of HIV infection and decrease barriers to HIV counseling and testing among this population. Included in this chapter is a description of the methods and procedures utilized in this investigation.

### **Study Design**

In an attempt to gain insight into Montana's Native American's experiences and perceptions, this investigation utilized a qualitative method of research. The purpose of qualitative research is to develop an understanding of individuals and events in their natural state, taking into account the relevant context. Qualitative research is predicated on the assumption that each individual, each culture, and each setting is unique. Furthermore, qualitative researchers consider it important to study and appreciate this uniqueness (Borg et al., 1996). Qualitative methods consist of three types of data collection: 1.) in-depth, open ended interviews (individual interviews or focus group interviews), 2.) direct observation, and 3.) written documents, including such sources as personal diaries and questionnaires. One or all three techniques may be applied. For the purpose of this study, focus groups were employed.

### **Description of Target Population**

The population investigated were members of the Salish and Kootenai tribes on the Flathead Indian Reservation in Montana. The reservation is an area of 1,250,000 acres of forested mountains and valleys west of the Continental Divide in Montana. It includes the south half of Flathead Lake. According to the Missoula Indian Center (1997), there are 6,889 members of the Salish and Kootenai tribes. The local economic conditions for the Salish and Kootenai Tribes as reported by the U.S. Department of Labor (1995) identifies 50.6% are unemployed and 14.9% are living in poverty. The Native American Advisory Council granted permission for focus group interviews to be conducted with members of the Salish and Kootenai tribes.

### **Protection of Human Subjects**

Consent forms and human subject application materials were completed in accordance with The University of Montana Institutional Review Board (IRB). The IRB determined this investigation did not constitute an unreasonable risk to human subjects and therefore granted permission for the study (see Appendix A).

## **PROCEDURES**

### **Selection of Sample**

Participants in the focus groups included Native Americans over eighteen years of age who reside on the Flathead Indian Reservation in Montana. These individuals were recruited through the reputational approach. The reputational approach involves identifying individuals reputed to have influence in the targeted population (Nix, et al., 1977). Participants included individuals who engage in high-risk behavior and members of the community who have experience working with individuals who engage in high-risk behavior. The Department of Public Health and Human Services (DPHHS) has identified high-risk behaviors as those behaviors that allow persons to come into contact with blood, semen, and vaginal fluids of HIV-infected individuals. These behaviors include vaginal and anal intercourse with persons infected with HIV/AIDS, and sharing hypodermic needles (DPHHS, 1995). The health educator at the Tribal Public Health Department contacted key informants reputed to have access to these high-risk groups. Key informants included employees of the tribal jail, teachers at the Two Eagle River School (an alternative school for high-risk students), and parents who are members of the Indian Teacher/Parent Council. These key informants solicited and organized focus group participants. An unsuccessful effort was also made to access Native American homosexual men who reside on the reservation.

## **Instrumentation**

The instrument utilized for data collection was a series of questions designed to pinpoint the needs of the tribal members concerning effective methods of HIV prevention techniques (see Appendix B). The questions were adapted from an Iowa Prevention Community Planning Group (Iowa Department of Health and Human Services, 1997) and were reviewed by tribal officials as well as tribal members in the target population. The instrument was designed to elicit information about HIV prevention. It contained several questions, each of which was followed by a series of additional questions aimed at getting richer, more detailed HIV prevention needs information. The instrument was pilot tested among a group of health educators at the Native American Advisory Committee (NAAC) meeting for HIV Prevention in Great Falls, Montana. It was then revised in order to evoke more effective and relevant discussion (see Appendix C).

## **Data Collection**

Data were collected from four focus groups. The health educator at the Tribal Public Health Department in St. Ignatius, Montana arranged the focus group interviews. Focus groups were conducted by three facilitators. One facilitator, the Health Educator at the Tribal Health Department, was responsible for asking the instrument questions. She was thoroughly trained and prepared for this task. The second facilitator, the researcher, was responsible for taking notes and recording her observations of the participants and their interactions. The third facilitator, the researcher's assistant, was present during these interviews to write participant responses on a flip chart. Writing responses allowed the

participants to focus their attention on the specific question at hand as well as enhance discussion.

Four focus groups were conducted. Participants included Native American health educators, members of the Indian Teacher/Parent Council, inmates at the Tribal Jail, and eighteen-year-old students enrolled at the Two Eagle River School. One interview session took place in Great Falls, Montana in January of 1998 and three sessions took place at various locations on the Flathead Indian Reservation in February of 1998. In appreciation of focus group participation, pizza and pop were provided.

Prior to each focus group, participants were welcomed, given a list of the questions to be asked, and verbally briefed on the proceedings. The facilitator assured the groups their identity would remain anonymous and provided each participant with an informed consent form. The facilitator reviewed the informed consent form while participants read and signed it to ensure each was aware of the inherent risks involved. In addition, a demographic information sheet was handed out and participants were asked to fill it out if they felt comfortable (see Appendix D). At this time, participants were made aware that the discussion would be audio-tape recorded and notes would be taken. Following each focus group, the researcher and her assistant then reviewed notes, discussed observations and commented on the overall interview. Audio-tapes were later transcribed by the researcher. Notes were checked for accuracy and exact quotations were verified from the transcribed audio-tape. Participants were thanked for their time and input.

## **Data Analysis**

Collected data consisted of notes taken during and immediately following the focus group interviews as well as transcribed audio-tapes of the focus group interviews (see Appendix E). For the purpose of this study, a qualitative transcript-based content analysis was utilized. Qualitative transcript-based content analysis involves examining the collected data manually in order to find constructs, general themes, and patterns (Krueger, 1994).

In the proposed study a qualitative transcript-based content analysis was performed by:

- 1) utilizing participant focus group narratives to describe their own attitudes, beliefs, and perceptions about HIV/AIDS issues. Focus group narratives provided a description of participants' analysis and interpretation of Native American HIV/AIDS concerns and issues;
- 2) analyzing indigenous themes, categories, and patterned regularities in focus group narratives. These themes and categories were generated and identified by participants in response to the researcher's questions;
- 3) contextualizing generated themes in a theoretical framework (social marketing).

Focus group data were analyzed for constructs, general themes and patterns within each focus group as well as across focus groups. To begin, the researcher read each of the audio-taped transcripts several times, annotating and highlighting key findings and potential quotes. The researcher searched the data for key points, reoccurring themes and general patterns that fit together, and/or were examples of the same underlying concept. Notes were made of reoccurring themes.

Following this, the researcher labeled large sheets of flip chart paper with each specific theme. Each theme had its own sheet of paper. Quotes from the audio-taped transcripts that fit together, that were examples of the same underlying theme, were manually cut and pasted onto the labeled paper accordingly. Quotes from each focus group that illustrated a particular theme were grouped together on the same sheet of flip chart paper. A code designating each focus group was written on a corner of the paper to allow the researcher to distinguish between focus group participant responses. This system made the data easier to analyze. Themes both within groups and common across groups were systematically organized and labeled.

Lastly, a preliminary summary of each focus group interview, as well as a list of identified themes for both within groups and across groups was prepared and submitted to the Native American health educator who assisted with the facilitation. This summary contained direct quotes, as well as the researcher's interpretations and observations of each focus group. The researcher asked the Native American facilitator to review, clarify, comment on and make any corrections she felt necessary to the information. The facilitator reported back promptly, confirming the accuracy of the summary.

Data from this study will be integrated into a social marketing theoretical framework. This information will assist health officials in developing a social marketing campaign. This campaign will be designed to increase perceptions of behavioral risk of HIV infection, decrease barriers to HIV counseling and testing in Montana's Native American population and aid health officials in developing culturally sensitive and effective social marketing interventions. Ultimately, the campaign will be used to combat this

deadly epidemic, potentially improving Native Americans overall health status and quality of life.



## **CHAPTER IV**

### **Results**

The purpose of this study was to assess the HIV prevention needs of Native Americans on the Flathead Indian Reservation in Montana. Subsequently, this information will be used to develop a social marketing campaign designed to increase perceptions of behavioral risk of HIV infection and decrease barriers to HIV counseling and testing among this population. Native Americans living on the Flathead Indian Reservation in Montana were interviewed using focus groups. The focus group interviews allowed the subjects to share their personal knowledge, perceptions and experiences involving HIV prevention with the researcher.

Four focus groups were conducted. Participants included Native American health educators, members of the Indian Teacher/Parent Council, inmates at the Tribal Jail, and eighteen-year-old students enrolled at the Two Eagle River School. One interview session took place in Great Falls, Montana in January of 1998 and three sessions took place at various locations on the Flathead Indian Reservation in February of 1998.

This chapter is divided into three sections. Section one provides a brief description of each focus group. Section two analyzes emergent themes and issues within each group and section three analyzes themes across focus groups. To illustrate and support each theme, verbatim responses from participants follow the theme descriptions.

## **Section One: Description of Focus Group Interviews**

### **Focus Group One: Native American Health Educators**

**Conducted: January 21, 1998 in Great Falls, Montana**

This interview session took place in a conference room at a local high school in Great Falls, Montana. Participants were Native American Health Educators from various towns and reservations in Montana, as well as members of Montana's Native American Advisory Committee (NAAC) for HIV Prevention. The group was seated comfortably around in a circle, casually dressed and conversing amongst themselves. Thirteen women and one male were present, including the researcher and her assistant. In the researcher's estimation, all were Native American and all were between the ages of 35 and 65 (no demographic information sheet was provided).

The purpose of this particular focus group session was to pilot test the questionnaire. It was important for the researcher to record the feedback from participants about the instrument and the session proceedings in order to ensure the effectiveness and relevance of future focus group sessions. In addition, the Tribal Health educator who was to be the facilitator in upcoming sessions was present to observe and take notes on how to facilitate focus groups and probe participants for richer, more detailed information about the issue at hand.

To begin, the researcher gave a brief summary of the proceedings and explained the purpose of the investigation. She encouraged participants to express their ideas, thoughts and concerns freely. A list of the questions to be asked was handed out and explained as

well as the informed consent form. Participants read and signed the informed consents and were made aware of the audio-tape recorder.

Throughout the interview session, participants were talkative and insightful. Each contributed to the discussion with only one, the eldest in the group, remaining completely silent. The session lasted one hour and ten minutes, with the mood remaining fairly light. Concerns and problems were addressed, discussed thoroughly and noted by the researcher. Participants were thanked for their time and input. Following the focus group session, the researcher and her assistant conversed and made additional notes and comments. The audio-tape was transcribed by the researcher. Prior to subsequent focus groups, the instrument was adjusted and revised according to feedback received from this initial session.

### **Focus Group Two: Indian Teacher/Parent Council**

**Conducted: February 4, 1998 in Pablo, Montana**

This interview session took place in a conference room at the Indian Tribal Complex in Pablo, Montana. Members of the community were gathered for a weekly Indian Teacher/Parent Council meeting. The focus group took place prior to one of these weekly meetings. Participants were teachers and parents in the community, on the Flathead Indian Reservation as well as members of the Indian Teacher/Parent Council. The group was seated around a table with others seated in nearby chairs. Thirteen women and four men were present, including the facilitator, the researcher, and her assistant. The majority of participants were married with children, Native American, and between the ages of

twenty-five and forty-four. (For further demographic information see appendix F.) Pizza and pop were served upon the arrival of the researcher and her assistant. The group ate and talked quietly amongst themselves.

To begin, the facilitator gave a brief summary of the proceedings and explained the purpose of the investigation. She encouraged participants to express their ideas, thoughts and concerns freely and assured them of their anonymity. A list of the questions to be asked was handed out and explained as well as the informed consent form and demographic information sheet. Participants read and signed the informed consents and were made aware of the audio-tape recorder and note taking.

Throughout the focus group, most participants were talkative and intuitive. One or two tended to dominate the discussion, but the facilitator was successful in including the entire group. Several times participants strayed from the topic at hand, but again, the facilitator was successful in keeping the group focused on the question. Two participants remained completely silent. Distracting to the interview session was the presence of two small children talking and walking about. Also, a few individuals were coming and going, exiting and entering the room. Despite these minor distractions, the group provided useful, insightful information and the discussion flowed smoothly. The interview session lasted an hour and forty-five minutes. The facilitator briefly summarized the main points, asked if anybody had any additional questions or comments, and then thanked participants for their ideas and support. The researcher and her assistant moved to a private location and reflected with the facilitator on the session. Notes were compared and the audio-tapes were later transcribed.

### **Focus Group Three: Inmates at the Tribal Jail**

**Conducted: February 25, 1998 in Pablo, Montana**

This interview session took place in a vacant room at the Tribal Jail in Pablo, Montana. Participants included inmates who were serving jail time for committing infractions of the law. The group was seated around a table in a circle, dressed alike in prison-owned garments. Eight male inmates and one female inmate were present. A prison guard, the researcher, the researcher's assistant, and the facilitator were also present. The majority of participants were Native American tribal members with children. Most had an annual income level below \$10,000. (For further demographic information see appendix G.)

Pizza and pop were served upon the arrival of the inmates. The group ate and talked quietly amongst themselves. To begin, the facilitator gave a brief summary of the proceedings and explained the purpose of the investigation. She encouraged participants to express their ideas, thoughts and concerns freely and assured them of their anonymity. A list of the questions to be asked was handed out and explained as well as the informed consent form and demographic information sheet. Participants read and signed the informed consents and were made aware of the audio-tape recorder and note taking.

Initially, the group was extremely quiet and reserved. When they did speak, they spoke softly and with hesitation. The inmates were not responding very emphatically to the questions and the facilitator struggled with their responses. One-word answers or sarcasm was often the common reply. After a considerable amount of time, the inmates began to open up. There was less sarcasm and hesitation and more interest and focus on the issue at hand. Participants seemed to be answering honestly, with genuine concern and

less humor. The bantering that was evident in the beginning slowly turned to earnest and serious responses. The only female inmate present did not respond at all. However, she was attentive and interested.

The inmates provided relevant, thought-provoking information. They were resourceful and had several innovative ideas. After nearly an hour and a half, the facilitator began to wrap things up. She briefly summarized the main points, asked if anybody had any additional questions or comments, and then thanked the inmates for their participation. The prison guard led inmates back to their cells and the researcher and her assistant reflected with the facilitator on the session. Notes were compared and the audio-tapes were later transcribed.

#### **Focus Group Four: Students at The Two Eagle River School**

**Conducted: February 27, 1998 in Pablo, Montana**

This interview session took place in a vacant classroom during the school day at the Two Eagle River School in Pablo, Montana. Participants were eighteen-year-old students enrolled at the school. The group was seated around in desks, forming a circle. Two women and nine men were present, not including the facilitator, the researcher, and her assistant. All participants were Native American. Pizza and pop were served upon the arrival of the students. The group ate and joked rambunctiously amongst themselves.

To begin, the facilitator gave a brief summary of the proceedings and explained the purpose of the investigation. She encouraged the students to express their ideas, thoughts and concerns freely and assured them of their anonymity. A list of the questions to be asked was handed out and explained as well as the informed consent form. For this group,

a demographic information sheet was not provided. Participants read and signed the informed consents and were made aware of the audio-tape recorder and note taking.

Throughout the interview session, students were talkative and vivacious. Some topics provoked more discussion and debate than others, however, the students were rarely silent. They asked several questions of the facilitator pertaining to the topic at hand, evidently due to misinformation they had received. It was apparent that participants needed assistance in separating myths from facts regarding HIV/AIDS information. One out of the only two women in the group remained completely silent while the other sporadically offered her input. Many of the men in the group offered stories or personal experiences. The facilitator was successful in keeping the discussion flowing smoothly and pertinent to the topic at hand.

Overall, the students offered valuable, useful information. Their input and ideas were clairvoyant and unique. After nearly an hour and a half, the students were required to return to their classes, provoking the facilitator to wrap things up. She briefly summarized the main points, asked if anybody had any additional questions or comments, and then thanked the students for their participation. Students returned to their respective classrooms and the researcher and her assistant reflected with the facilitator on the session. Notes were compared and the audio-tapes were later transcribed.

## **Section Two: Analysis of Themes Within Groups**

Data were analyzed for constructs, general themes and patterns within each focus group. Several reoccurring themes and patterns were evident within each individual group. This section describes the themes within each group followed by verbatim quotes supporting these themes.

### **Focus Group One: Native American Health Educators**

#### **Indian Youth**

The central theme in this focus group was Indian youth. Generally, participants perceived adolescents to be the most at-risk for HIV infection and felt that more HIV education is needed among this age group. The following are sub-categories of data regarding Indian youth and HIV/AIDS reported by Native American health educators:

##### **1) Native youth need more HIV/AIDS information**

This focus group believed Native American youth have many questions concerning HIV and are unsure of where to go or who to go to for information. The group thought Indian youth lack a place to go where they feel safe, where they can talk to somebody openly and honestly. They felt adolescents need to be able to express concerns and ask questions about HIV/AIDS. Moreover, this focus group perceived young people want “straight facts,” they want to be able to decipher factual information from fictitious information. In addition, focus group participants who have experience working with Native youth perceived adolescents are not aware of at-risk behaviors and engage in them unknowingly, putting themselves at risk:



“The kids had all these questions about testing and what is testing like and they don’t know where to go or who to go to.”

“Young people need a place to go where they can feel safe. They seem to need a place to go where they can talk to somebody. There are some in the community, you know, where all the kids go and it’s just a good thing when they can identify those [people] in the community. Maybe you can start teaching that parent to maybe talk a little bit about this and that...”

“I just give them straight facts. Straight, factual information. That’s what they want.”

“To me, it’s like the kids have all these questions and like the worst thing is, they don’t realize, they don’t realize these at-risk behaviors that they are going through and you know...”

## **2) Confidentiality may be an issue with some Native youth**

Focus group participants perceived some Native youth may feel uncomfortable or ashamed seeking help on the reservation because of confidentiality issues and therefore, do not get tested for the virus.

“They, you know, they don’t want to say anything to anybody, or ask any of their friends, you know, they’re too ashamed. They don’t want anybody to know...”

“One of the concerns we talked about is confidentiality and some of the kids at school said they wouldn’t go [for help] local because they wouldn’t want anyone to know they were concerned. They would rather go somewhere else...somewhere off the reservation...”

## **3) Condom use and lack thereof**

Focus group participants made several references to condom use and the lack thereof.

They expressed that many sexually active Native youth are unsure of proper and effective condom use. One participant remarked that some sexually active adolescents have little or no experience with condoms and condom application. She felt Native youth needed more practice and “hands on experience.”

“I know I’ve asked some of the young men if they’ve ever put a rubber on...or I talk to the girls and ask them if they know what a rubber feels like, and I get alot of giggles...but, you know, you can say, ‘Use a condom!’ all day long but unless their actually willing to touch the damn thing, you know, and play with it and see what it feels like and stuff, I mean, they’re not even gonna try...”

“...they need some, excuse the pun, hands on experience. You know, you can tell them they need to use condoms but if they’re kind of nervous about using them or not quite sure how to use them or think they’re going make fools out of themselves they won’t use them...”

#### **4) Native adolescents do not perceive HIV/AIDS risk**

Focus group participants regarded Montana’s adolescent’s as naive in their beliefs concerning HIV/AIDS. Participants believed Native youth think HIV/AIDS has not reached Montana, that it occurs only in the larger cities and only within the homosexual or drug user population. In addition, participants perceived Native young people are unaware of the statistics regarding HIV/AIDS cases in Montana and in Lake County. One participant remarked:

“I think people think you have to be a homosexual or a drug user or whatever but there are other ways to get it that may be associated with anyone...”

“...and I’m finding that they have no idea the amount of cases we have in Montana. They think, ‘Oh, we don’t have anything like that here.’ When I start telling them, it’s like, ‘Oh, I had no idea it was that close...I didn’t know there was that many people...’”

## **Focus Group Two: Indian Teacher/Parent Council**

### **HIV/AIDS Education**

The central theme in this focus group was HIV/AIDS education. Generally, participants felt more HIV/AIDS education is needed in the community. The following are sub-categories of data regarding HIV/AIDS education reported by the Indian Teacher/Parent Council:

#### **1) Heighten HIV/AIDS awareness**

Participants in this focus group believed the central problem with HIV prevention in their community is the tendency for individuals to not discuss HIV/AIDS. The group stressed the importance for the community to get over “the spin” of not discussing the issue and instead, heighten the awareness level. They perceived the issue of HIV/AIDS has been downplayed, resulting in many individuals feeling as if it is nonexistent within the community.

“Not talking about it, ignoring it, is just not going to work.”

“I think the community needs to get over the spin of not discussing it and recognize that it’s there whether you like it or not and decide how your community is going to deal with it...and give us some ammunition to deal with it...if they don’t have that then they can’t deal with it...”

“You know, I think this AIDS has been downplayed a bit, lately, you never hear a whole lot about it. As a result we have a whole bunch of young people who are just coming into this active age group who think, ‘Oh, nobody’s got it, nobody’s got it here in Montana, or it’s no big deal anymore...or that was three years ago’s problem, it’s not this year’s problem.’ Just the awareness...I think people need to be constantly reminded that it’s not a safe world out there...AIDS is still there despite the fact new drugs are out that reduce the rate of death, that doesn’t mean that AIDS is gone...there’s still no cure...we need to keep the awareness up, keep the message going...”

## **2) Adults do not know how to discuss HIV/AIDS**

The council felt parents and members of the community do not know how to talk to children about HIV/AIDS or about the concerns related to the epidemic, thus ignoring the issue. Several participants felt that parents, teachers and members of the community are lacking in knowledge about HIV/AIDS and are unsure of what is myth and what is actual fact. Consequently, they have difficulty answering questions about the disease.

“We need to teach people how to talk about it, how to talk to their kids and the little ones around...”

“I think being direct and basically being honest about it, I mean people want to hear honestly and direct...at this point, nobody knows what to believe...”

## **3) Incorporate HIV/AIDS information into daily lives**

In addition to the need for more HIV/AIDS education among adults, participants stressed the importance for this information to be incorporated into their daily lives, as part of their daily routine:

“The information needs to be incorporated into something that we’re forced to do but, in addition, we get that information so we wouldn’t have to take time out of a busy schedule...something that we have to do anyway...like when we’re at a tribal staff meeting, or when we line up to get buffalo meat...I mean there are all kinds of ways...the captive audience thing, piggyback it onto something else...incorporate it into our daily lives...”

“Put a little statement in front of every video machine and you’ll probably educate alot of people...put it in our paychecks...in an easy spot but nevertheless available...make it easier for us...”

#### **4) Increase HIV/AIDS education in schools**

Several participants related stories about the uproar previous HIV/AIDS education has caused in the schools, such as HIV positive speakers. Participants would like members of the community who have problems or concerns with schools providing HIV/AIDS education to be addressed. The group commented on the importance of culture conducive, age appropriate HIV/AIDS education in the schools. Many would like to see stories targeted specifically at youths that include graphic examples depicting the seriousness and hopelessness of HIV/AIDS. Furthermore, participants felt HIV/AIDS education should begin at a young age but without forcing the issue on the parents or the youth.

“Last year somebody came into the school to talk about it and there was a big ruckus...it shouldn't have to be such a battle with that kind of information...it shouldn't be such an uproar and if there is going to be then we need to find out who's got a problem with it and go to them and actually encourage them and ask them to help design an educational component...”

“I would like to see some youth related stories...for kids to see youths, not so much adults that have had it...testimonial type stuff...and age appropriate. Also, if you're helping other tribes I think it's important to make it culture specific, alot of tribes have different cultures that stress different values...it needs to be culture conducive...”

“I think you need to show examples of it too...the seriousness of it, of the condition, the hopelessness of it so it starts to become more of a reality. Messages need to relay just how serious it is...you could die...it's not just a health risk anymore, it's a matter of life.”

### **5) Break the misconceptions and stereotypes of HIV/AIDS not in Montana**

Participants remarked on the need for the community to break the stereotypes and get over the misconception of HIV/AIDS not occurring in Montana. Participants felt the number of Montanans with AIDS and who have died from AIDS is virtually unknown by most Native Americans.

“I think too that we need to focus on that it does happen in Montana...people just don’t know the number of cases here in Montana, that would shock most people...that’s why I think that breaking the stereotypes is really important because there’s a stereotype that happens that brings up the homophobia and all those things...the idea that I’m not at risk when the risks are there...”

“...like those statistics have said, you know, people don’t read those when they should...”

### **Focus Group Three: Inmates at the Tribal Jail**

#### **HIV/AIDS Prevention**

The central theme in this focus group was HIV/AIDS prevention. The group discussed HIV prevention techniques such as clean needles, condoms and HIV testing. The following are the sub-categories of data regarding HIV/AIDS prevention reported by Tribal Jail inmates.

#### **1) Intravenous drug use and needle sharing is reality**

In terms of HIV/AIDS prevention, this group’s central focus was intravenous drug use and needle sharing. Participants perceived drug enforcement to be “lagging behind.”

They remarked that anybody can get drugs, at any time, if they wanted to. The general consensus was that drugs were available everywhere and many Native people are doing them, both on and off the reservation. In addition, many intravenous drug users simply

don't care about the risks involved with needle sharing, they are not afraid to die. They perceived individuals who use drugs and share needles know the risks, but feel the high is more important. Furthermore, many participants felt that supplying drug users with clean needles would help the situation, while others believed it would provoke drug use.

"Drug enforcement really lags behind...the availability of it is high, you can get that shit anywhere..."

"Drugs are out there, they're everywhere, man."

"I think people that do use needles and do use dirty needles, I think they probably realize, they know what they're doing and how dangerous it is. I'm pretty sure of that...they're the ones who know the best. It's just that the burn inside is more important, the high is more important...I mean someone who shoots up, I don't think they even care."

"Well, if it's out there on the street, they're going to get a needle somewhere. If the dope's there, they'll get a needle somewhere. It's better to have clean needles out there than 4 or 5 people sharing the same needle."

"If they're going to be shooting up, they should have access to clean needles, that way they don't share."

"If you're going to start giving free needles, it's going to spread more..."

## **2) HIV/AIDS is not real**

Participants in this focus group have a strong belief they are not susceptible to HIV/AIDS. They feel it's almost "not real" and would never happen to them.

"I don't think I'll ever get AIDS. It's something I know, like I'll never get cancer, I'll never get anything life threatening. It's a feeling you happen to have, you know, you don't want to run around scared all the time, thinking you'll be dead or something...that's just the way I am..."

"It's almost like not real, man."

"It's never going to happen to me so I don't worry about it. With me, I don't picture myself with AIDS so I don't bother reading nothin' about it."

### **3) HIV/AIDS education should be graphic and real life**

In terms of education, the inmates perceived visual, graphic examples of individuals affected by HIV/AIDS as having the most profound effect on changing their at-risk behaviors. In schools, they perceived HIV positive speakers to be more effective than HIV negative speakers. Moreover, they believed HIV/AIDS education is needed not only with the very young in the community but also with the local parents. Participants remarked on the importance of the adults being able to answer any questions or address any concerns the Native youth may have.

“Seeing a person who does have it...now that would make me think...I want to hear it from someone who does have it...”

“It’s good to start with the parents, ‘cause if the parents got the information and the young ones need some help, they can go to them.”

“Get to the young people...”

### **4) Ambiguous feelings about condoms**

It was apparent that many of the inmates have not been practicing safe sex. When asked about condoms, one older participant remarked that he has “never used them in the past and was not going to begin now.” Another commented on how many of his friends, many older individuals, “weren’t raised in the AIDS generation and don’t use condoms.” He said he was “choosy” about his partners and therefore, felt no need for them. The group agreed they do not get the same feeling with a condom as without. Condoms and sensitivity, or the lack thereof, was an issue. Ironically, participants felt more condom distribution and condom information is necessary in schools. Participants perceived Native youth are unaware of proper and effective condom use.



“I’m in my mid-thirties and alot of people my age wouldn’t bother using condoms, it’s like a stigma...I didn’t use them then, I ain’t gonna use them in the future...I wasn’t raised in the AIDS generation.”

“You can’t teach an old dog new tricks...I mean they’ve gotten this far without them...”

“Personally, I wouldn’t use a condom...I never did...I always knew my partners and I’m choosy.”

“I think that’s the main issue, you don’t get the same feeling.”

“Just give ‘em out, man. Just have ‘em out everywhere, everyday...”

### **5) Mandatory HIV/AIDS testing is needed**

In terms of HIV testing, the inmates felt that everybody should be tested. They believed mandatory testing for all Native Americans in the community, including professionals such as doctors, health professionals, and police officers is essential. Several participants felt the community is scared to get tested and have some confidentiality issues. One inmate remarked on the apathy of some individuals concerning testing. He added that some individuals feel it’s useless, and have an “everybody is going to die anyway” attitude.

“I think the professionals should get tested too, police and health professionals, like a requirement, jailers and doctors...”

“Some people I talk to about it, I told them I was scared to get tested and they said they were and some other people were like, ‘Who cares? Everybody’s gonna die anyway...’ More than one person has said that to me...”

“One thing about the reservation though, it’s such a small community and everybody knows everybody, and you tell one person you got tested, and it don’t matter if you got it or not but within a week, even if it came back negative or positive, it goes down the grapevine, you know, your full-blown by the time it goes down the grapevine about 4 or 5 people and you know everybody’s looking at you like, the guy’s all full-blown AIDS...stay away from him...”

## **6) Unaware of HIV/AIDS statistics in Montana**

Lastly, this group was unaware of the statistics regarding HIV/AIDS cases in Montana and in Lake County. They perceived others to be unaware as well.

“People don’t think AIDS is around here, we don’t see anybody with it...nobody around here dies from it...”

“Why do they have to keep it so confidential? Like who has it? Because what if you like sleep with them and you don’t know they got it, they don’t tell you, then you get it and you sleep with somebody else, then you don’t know who got it and they don’t know you got it and it just spreads and nobody finds out till a month or so and there could already be so many cases. There should be some list or something...or at least a number of people for each town, and if they go in and get tested and are positive add them on so your aware of how many people got it.”

## **Focus Group Four: Students at The Two Eagle River School**

### **HIV/AIDS Information**

Participants in this focus group stressed the importance of more HIV/AIDS information. The following are sub-categories of data regarding HIV/AIDS information reported by Native American students.

#### **1) Factual HIV/AIDS information is needed**

Students felt there is too much “bad” information circulating and would like adults to spread the same, factual message. They want this factual information from “the top researchers.” All of the students agreed they have difficulty deciphering factual information from fictitious information. It was evident in their responses, as well as their questions, they are bewildered when it comes to HIV/AIDS information. Participants were unsure of who or what to believe. Repeatedly, these students remarked on their need for “hard” facts, “first-hand,” from the “top researchers.”

**“You hear different stories from different people and then you ask the professional and they get confused because there are too many things going around. Some true, some not true. So you ask your grandma and doctors and teachers and they all tell the same story and different stories. We want the same story, instead one then the other...which one do I believe?”**

**“I want the information from the top researchers that are doing this, the top researchers know more and the best way and all that, I want to get it from them. Because did you ever play that one game where you tell a person like that and you have to tell a person and it gets down the line and it gets all messed up. That’s how it basically is...it gets all messed up, everybody adds in their own little bit.”**

## **2) More HIV/AIDS education is needed**

In terms of education, participants stressed the importance of more HIV/AIDS education and awareness. HIV infected speakers was a major issue. The majority of the students felt the Native youth would take HIV/AIDS more seriously if HIV infected individuals spoke at school. Others expressed concern about the presence of HIV infected individuals near them. One female participant said she “thinks it’s scary.” Another commented, “I don’t want to eat in the same lunch room.” Generally, they would attend more HIV/AIDS education/awareness events if they were close to home and offered free food. The group agreed HIV/AIDS education should begin at the age of thirteen and should emphasize the fact there is no cure. One remarked that thirteen was the age he started asking questions. Otherwise, they concurred, younger Native Americans tend not to be mature enough to handle the HIV/AIDS information, specifically, condom information. In addition, they believed HIV/AIDS information should not be mandatory, that it would be taken more seriously if it was voluntary.

**“I want to get it [HIV/AIDS information] from a person who’s actually infected from it, because then without a doubt I would really start thinking about it...after they told me everything...because, actually, why have someone talk to you that don’t have it? That would bring like more attention too because someone infected**

by it, they'll [kids] listen more. Somebody should talk to you that does have it, that knows what's going on. Then you'll know the facts..."

"I think that's what you need, somebody who has it [HIV/AIDS] to speak out to tell people and tell them how it is. I think that would make young people think about it, take it more seriously..."

"I'd go if it was close to my house and I could just walk or if I had a ride up and back. Maybe if there was free pizza too."

"Thirteen, that was like the average age when people wanted to, you know, do it. That's when they really start getting into it..."

"Thirteen's when I started listening, before that I wasn't even listening..."

"If they have to go they ain't gonna listen. They'll lose track of what they're supposed to be listening to and messing around and getting in trouble and stuff..."

"If they just go on their own, then that's when you know whether people really want to listen or not."

### **3) Unsure of proper condom use**

Condoms were a topic continually accentuated throughout the focus group. It was apparent in their questions and responses that many were unsure of proper condom use. A few participants relayed personal experiences with condoms breaking. Others felt "nobody ever does use condoms because they're uncomfortable and they take the feeling away." Other excuses for not using condoms included, too embarrassed to get them, "don't feel like going to the store at 1:00 in the morning" to get them, and "don't have one." The group agreed that women should carry condoms and encourage their partners to use them. The young male participants felt it is no longer the "guy's" responsibility. In terms of condom distribution, the students felt condoms should be available and distributed all the time, especially on Fridays.

"About the condom thing, man, when your doing it with a condom on sometimes the condom might slide off and it might get stuck up there and stuff and sperm will

still get out and stuff, or it might break. Even with the condom, man, you can still get AIDS...”

“That’s the whole problem, nobody ever does use condoms...”

“Some people’s excuse is they take the feeling away, they’re uncomfortable...”

“I don’t use them all the time because I don’t have them all the time. You never know when your gonna smack [have sex]. When you’re drunk you don’t care anyway...”

“Sometimes, man, the girls don’t want to use them and sometimes they do...”

“It’s easier if someone just gives them [condoms] out than to have to ask for them. They should give them out every weekend, every Friday, have them available at any time...”

#### **4) Students will risk HIV/AIDS infection**

Several students commented on how they’re willing to take the risk of contracting HIV now because they fear the epidemic will only worsen. One participant perceived half the town already has HIV but is unaware of it. He felt that nobody “bothers” to get tested, that the community is too scared to do so.

“...when they might find a little better cure I’ll probably stop taking the risk but for now I’m willing to take the risk...”

“I mean cause it’s getting worse and worse by this time next millennium or so there will be nothing left...I’d rather take my chances now...”

“I’m willing to take the risk [of HIV infection], it’s worse in a small town than it is in a big town. Probably everybody in half this town has it and nobody knows it. No one really knows, no one gets checked, they’re probably too scared to go in. It’s just a risk I’m willing to take...”

“It’s dangerous as it is already, you can die from anything, man. The doctor’s always sayin’ you can eat this, you can’t eat that...I mean, it’s gettin’ worse and worse, man, anything you do is dangerous. If I’m going to die of AIDS, I don’t want to die slow, I’d rather just go do something to get killed like rob a bank or get killed by a bear, anything. Everything’s a risk if your willing to take it, just take it man, don’t cry about it. Life’s a risk, man...”

### **5) There is no HIV/AIDS in Montana**

Many students in the group were concerned with the community's attitude concerning the prevalence of HIV/AIDS in Montana. Several participants remarked that many of their peers "don't think they can get it because this is small town Pablo." Some students equated HIV/AIDS with large cities, not Montana. The group was unaware of the statistics regarding HIV/AIDS cases in Montana and in Lake County. However, they believed the number is important and should be more widely known.

"The thing is, it's the same thing with this AIDS stuff...here in small town it grows a lot faster, the chances are even worse..."

"In a city all this shit is different, man. But down here in Pablo, I don't know, it's just different. In a city you live your days day by day cause of all the killing. This is just small town Pablo, I just don't know what else to say..."

"Down there [the city] you get killed by bullets and everything. Not here, but here you pretty much hear about anything...you'd know who had it."

### **6) Students feel the community is apathetic about HIV/AIDS**

Towards the end of the focus group, the overall tone of the participants was one of hopelessness and pessimism. The group perceived the community as not caring about HIV/AIDS. One participant perceived older people don't care and don't give the "good messages," therefore that is why "bad information" circulates. In their opinions, a major problem on the reservation is the lack of seriousness among the Natives regarding the epidemic. As a whole, the student's attitudes were "No one takes it seriously enough." One young man continually spoke of the apathy permeating the community. "Just make people care more about it," he said.

"Like I said, most people don't care till it's too late..."

“People just don’t care that much. More and more people are starting to care but it’s just not enough to start putting a dent in it...because most people I know they don’t care if they have it or if they get it...”

“Make them care, man. You can sit there and talk to them and talk, if they [kids] grow up the way they [adults] did, they won’t care until it’s too late. I mean they didn’t care much about anything when they were growing up...most of them now don’t care, all they like to do is have fun and party.”

“...just make them care, man, really push them, make them care, make them sound serious because it’s in one ear and out the other...start preaching then they’d probably start caring after awhile.”

### **Section Three: Analysis of Themes Across Groups**

Data were analyzed for constructs, general themes and patterns within each focus group and across focus groups. Experiences related by participants in each focus group varied. There were, however, basic themes that emerged from analysis of the focus group data which were repeated across groups. This section describes the themes evident across focus groups followed by verbatim quotes supporting these themes.

#### **HIV/AIDS misinformation**

The most dominant theme imbedded within all focus groups was the problem of misinformation regarding HIV/AIDS. Each group stressed the importance of receiving factual HIV/AIDS information. With the exception of the first focus group, the Native American health educators, all participants in the remaining three groups agreed they have difficulty deciphering factual HIV/AIDS information from fictitious HIV/AIDS information. However, the Native American health educators group was the exception due to the fact they were health educators, well versed in HIV/AIDS information. Although the Native American health educators group were knowledgeable regarding HIV/AIDS, they were aware of the myths surrounding HIV/AIDS. Native American health educator participants felt there was an urgency to dispel these myths within Native American communities, specifically Native youth. In their opinion, Native youth want “straight facts.”

It was evident in the other three group’s responses, as well as their questions, they were bewildered when it came to HIV/AIDS information. They were unsure of who or what to believe. In the Indian/Parent Council group, one participant relayed an experience in which she had been attempting to encourage townspeople within her community to



raise the chlorine levels in the public pool to ensure the HIV/AIDS virus does not live within the pool. Another participant in that same group believed HIV/AIDS information should be disseminated in dentist's offices because "that is where the virus can be transmitted very easily." In the second group, the inmates at the Tribal Jail, one participant spoke of his fear of hospitals. He's refused to ever receive a blood transfusion because of the possibility of HIV transmission. At the focus group involving students at The Two Eagle River School, it was apparent there was a plethora of fictitious HIV/AIDS information circulating among this age group. One student believed HIV/AIDS originated due to an American having intercourse with a monkey. Another said he heard individuals can contract HIV/AIDS if they have intercourse with an HIV infected woman while she is menstruating, regardless of whether or not the man is wearing a condom.

Retrospectively, the Two Eagle River School group was most confused regarding HIV/AIDS information. This group had more questions and relayed many more experiences reflecting their confusion concerning HIV/AIDS information than any other group. Clearly, they were misinformed and unsure of who or what to believe. Repeatedly, these participants remarked on their need for more "hard," factual HIV/AIDS information, "first-hand," from the top researchers. They were frustrated with the continual circulation of HIV/AIDS misinformation. Participants in the Native American health educators focus group were correct in their assumption that Native youth want and need "straight, factual HIV/AIDS information."

***Native American health educator participant:***

"...they want straight, factual information. That's what they want. That's what they need."

***Indian Teacher/Parent Council participants:***

"...and they've still not found the right level of chlorine in a public pool to kill an AIDS virus..."

"...I think [there should be] pamphlets in the dental clinics where AIDS can be transmitted very easily..."

***Tribal Jail participant:***

"I'm scared of the hospital, man...those blood transfusions..."

***Two Eagle River School participants:***

"...I heard someone had sex with a monkey..."

"...yeah, like I've heard stories about people earning their red wings...so like that, you might have used a condom when they're on their period but like 10 years down the road you have it [HIV/AIDS] and you say, 'I used a condom, man'...but the red wings, man, just that one little thing screwed up your life and like many others you didn't even know about it till it's too late..."

"I want the information from the top researchers that are doing this, the top researchers know more and the best way and all that, I want to get it from them. Because did you ever play that one game where you tell a person like that and you have to tell a person and it gets down the line and it gets all messed up. That's how it basically is...it gets all messed up, everybody adds in their own little bit."

"You hear different stories from different people and then you ask the professional and they get confused because there are too many things going around. Some true, some not true. So you ask your grandma and doctors and teachers and they all tell the same story and different stories. We want the same story, instead one then the other...which one do I believe?"

"There's lots of bad information out there, like you can't get pregnant on the first time..."

## **HIV/AIDS awareness in Montana**

Participants in all four focus groups believed there needs to be a heightened sense of awareness in the community regarding HIV/AIDS. Each focus group spoke of the belief held by many in the community that HIV/AIDS is nonexistent in Montana. Participants perceived many Native people to maintain the attitude that HIV/AIDS “hasn’t reached Montana yet.” The Native American health educators group believed Native youth are most prone to uphold the belief that HIV/AIDS is “not around here.” Many participants in the Tribal Jail group maintained they do not believe they are susceptible to HIV/AIDS. This belief may possibly be a result of the underlying notion that HIV/AIDS is nonexistent in Montana. One Tribal Jail inmate remarked he didn’t think he could get HIV/AIDS, adding “it’s just a feeling I have.” Another Two Eagle River School participant repeatedly commented on the apathy of the community regarding HIV/AIDS transmission. He perceived the community as “not thinking it’s around here” and therefore, not caring and perhaps not using preventative measures. Also, he continuously associated HIV/AIDS to larger cities, not to “small town Pablo.” Indian Teacher/Parent Council participants stressed the importance for the community to get over “the spin” of not discussing the issue. This group believed HIV/AIDS has been widely downplayed and/or ignored in the community leaving many Natives feeling as if it is nonexistent within the area.

Furthermore, the number of AIDS infected individuals living in Montana, specifically on the reservation is unknown among the community. Participants in all groups, with the exception of the Native American health educator group, were unaware of the statistics regarding AIDS infection in Montana and in their own community (Lake County).

Although Native American health educator participants are knowledgeable about AIDS statistics, they believe others, especially Native youth, are unaware of these numbers. Participants in all groups agreed there needs to be an enhanced level of HIV/AIDS awareness in the community, specifically regarding the number of AIDS cases in Montana and in surrounding areas.

***Native American health educator participant:***

“...and I’m finding that they have no idea the amount of cases we have in Montana. They think, ‘Oh, we don’t have anything like that here.’ When I start telling them, it’s like, ‘Oh, I had no idea it was that close...I didn’t know there was that many people...’”

***Indian Teacher/Parent Council participants:***

“I think the community needs to get over the spin of not discussing it and recognize that it’s there whether you like it or not and decide how your community is going to deal with it...”

“You know, I think this AIDS has been downplayed a bit, lately, you never hear a whole lot about it. As a result we have a whole bunch of young people who are just coming into this active age group who think, ‘Oh, nobody’s got it, nobody’s got it here in Montana, or it’s no big deal anymore...or that was three years ago’s problem, it’s not this year’s problem.’ Just the awareness...I think people need to be constantly reminded that it’s not a safe world out there...AIDS is still there despite the fact new drugs are out that reduce the rate of death, that doesn’t mean that AIDS is gone...there’s still no cure...we need to keep the awareness up, keep the message going...”

“Not talking about it, ignoring it, is just not going to work.”

“I think too that we need to focus on that it does happen in Montana...people just don’t know the number of cases here in Montana, that would shock most people...the idea that I’m not at risk when the risks are there...”

***Tribal Jail participants:***

“I don’t think I’ll ever get AIDS. It’s something I know, like I’ll never get cancer, I’ll never get anything life threatening. It’s a feeling you happen to have, you know, you don’t want to run around scared all the time, thinking you’ll be dead or something...that’s just the way I am...it’s just a feeling I have...”

“It’s never going to happen to me so I don’t worry about it. With me, I don’t picture myself with AIDS so I don’t bother reading nothin’ about it.”

“People don’t think AIDS is around here, we don’t see anybody with it...nobody around here dies from it...”

“Why do they have to keep it so confidential? Like who has it? Because what if you like sleep with them and you don’t know they got it, they don’t tell you, then you get it and you sleep with somebody else, then you don’t know who got it and they don’t know you got it and it just spreads and nobody finds out till a month or so and there could already be so many cases. There should be some list or something...or at least a number of people for each town, and if they go in and get tested and are positive add them on so your aware of how many people got it.”

***Two Eagle River School participants:***

“In a city all this shit is different, man. But down here in Pablo, I don’t know, it’s just different...this is just small town Pablo, I just don’t know what else to say...”

“Down there [the city] you get killed by bullets and everything. Not here, but here you pretty much hear about anything...you’d know who had it.”

“People just don’t care that much. More and more people are starting to care but it’s just not enough to start putting a dent in it...because most people I know they don’t care...and the whole problem is nobody ever does use condoms.”

## **HIV/AIDS testing**

HIV/AIDS testing within the community was a dominant theme among participants across all four focus groups. Two Eagle River School participants perceived “nobody gets checked” in the community. One participant in this group believed every couple who plans on getting married should be required to go in and get an HIV/AIDS test. Another participant believed “everyone’s probably too scared to go in and get checked.” Ironically, one participant in the Tribal Jail group mentioned he was “scared to get tested” and knew others who felt the same. Other inmates in the Tribal Jail group thought every individual who gets placed in jail should be required to take an HIV/AIDS test. One participant in this same group mentioned mandatory testing for all members of the community, specifically for professionals such as police officers, doctors, and other health

professionals. Several Tribal Jail participants perceived individuals in the community to have confidentiality issues and therefore, fail to get tested.

***Native American health educator participant:***

“...and so it really worked out good because we had an opportunity to test 16 to 18 year kids and when you’re testing you don’t see that population come in even though they really should...”

***Indian Teacher/Parent Council participant:***

“...so I called to see if they would be running AIDS tests because I think that would be a great window of opportunity...give some info and test people confidentially...I mean with adults so we have to wait? How big do the numbers have to be...?”

***Tribal Jail participants:***

“...yeah, some people I talk to about it, I told them I was scared to get tested and they said they were too...”

“I think the professionals should get tested too, police and health professionals, like a requirement, jailers and doctors...”

“One thing about the reservation though, it’s such a small community and everybody knows everybody, and you tell one person you got tested, and it don’t matter if you got it or not but within a week, even if it came back negative or positive, it goes down the grapevine, you know, your full-blown by the time it goes down the grapevine about 4 or 5 people and you know everybody’s looking at you like, the guy’s all full-blown AIDS...stay away from him...”

***Two Eagle River School participants:***

“When your gonna get married, you should have to go get checked...”

“...nobody does get checked...everyone’s probably too scared to go in and get checked...”

## **HIV/AIDS education for parents**

With the exception of the Two Eagle River School group, participants in the remaining three focus groups remarked on the importance of HIV/AIDS education for parents, as well as HIV/AIDS education for other adults in the community. However, Two Eagle River School participants when asked where they receive HIV/AIDS information, mentioned parents as information sources. Other adults referred to by students as sources of HIV/AIDS information were grandmothers, aunts, uncles, teachers, and counselors. In addition, Indian Teacher/Parent Council participants felt there should be some way to address those in the community who have problems concerning HIV/AIDS related events in schools. One participant in this group relayed an experience in which an HIV positive person spoke at Ronan High School several years ago, causing an uproar in the community. This participant believed there should be an educational information session specifically for those adults who object to HIV/AIDS related events, in addition to information sessions for every adult in the community.

The group agreed members of the community need to be encouraged to help design an educational component for local schools. This would not only enable adults to receive HIV/AIDS information but it is also an opportunity to address those in the community who have a problem with HIV/AIDS related events. Members of the community who object to such events can be educated on the seriousness of HIV/AIDS as well as the benefits of these events. More importantly, this group believed the community needs to be taught how to talk about HIV/AIDS, they need some “ammunition to deal with the issue,” enabling them to address any questions Native youth may have.

Lastly, participants in both the Indian/Parent Council group and Tribal Jail group perceived the most effective way to reach adults is through the “captive audience” approach. That is, incorporating HIV/AIDS information into their daily lives, their daily routines. Indian Teacher/Parent Council participants mentioned short statements of HIV/AIDS information facts submitted into paychecks or placed onto the front of video poker machines would be helpful. Tribal Jail participants perceived DUI (driving under the influence of alcohol or drugs) classes to be an effective way to disseminate HIV/AIDS information.

***Native American health educator participants:***

“...if we could just get a packet of information to the parents that are willing to help kids...”

“...those in the community...you can start maybe teaching that parent to maybe talking a little bit about this and that...”

***Indian Teacher/Parent Council participants:***

“...give us some ammunition to deal with it [HIV/AIDS]...if they don’t have that then they can’t deal with it...”

“We need to teach people how to talk about it, how to talk to their kids and the little ones around...”

“Last year somebody came into the school to talk about it and there was a big ruckus...it shouldn’t have to be such a battle with that kind of information...it shouldn’t be such an uproar and if there is going to be than we need to find out who’s got a problem with it and go to them and actually encourage them and ask them to help design an educational component...”

“The information needs to be incorporated into something that we’re forced to do but, in addition, we get that information so we wouldn’t have to take time out of a busy schedule...something that we have to do anyway...like when we’re at a tribal staff meeting, or when we line up to get buffalo meat...I mean there are all kinds of ways...the captive audience thing, piggyback it onto something else...incorporate it into our daily lives...”



***Tribal Jail participants:***

"It's good to start with the parents, 'cause if the parents got the information and the young ones need some help, they can go to them..."

"...when you go to DUI class, show a video about it [HIV/AIDS]."

"...maybe get it [HIV/AIDS information] while in jail...because one thing about jail is it gives you a lot of time to think so you think that you might've contracted this...people are here sobering up and stuff like that they can think...while their living out in the regular world, they don't want to do that..."

***Two Eagle River School participants:***

"...my grandmother talks about it all the time...she knows it all..."

"...at home...parents, grandparents or aunties and uncles..."

**HIV-infected speakers**

Participants in all focus groups with the exception of the Native American health educator group, perceived HIV infected speakers to be most effective in terms of HIV/AIDS education. No reference, positive or negative, was made to HIV infected speakers at all during the Native American health educator focus group interview.

Although it was a major theme in the other three focus groups, Two Eagle River School student participants continuously commented on the impact of HIV positive speakers.

One participant in this group repeatedly referred to an HIV infected individual who spoke at an HIV/AIDS related event she attended in Billings, Montana. It was evident this young student was greatly impacted by the HIV infected speaker. Two Eagle River School students believed HIV infected speakers would heighten HIV/AIDS awareness, ultimately curbing HIV transmission. In addition, participants in each group also believed graphic, visual examples of HIV/AIDS infected individuals have significant impact.

***Indian Teacher/Parent Council participants:***

"I think you need to show examples of it too...I think the graphic examples are really hard...even for adults...when you see it, it starts to become more of a reality..."

"...have people come in and talk about the events that have happened to them...testimonial type stuff..."

"...make it real for me..."

"I would think you get an understanding of what someone who has HIV goes through...and there's a lot of medical expense and a lot of attention and the ramifications..."

***Tribal Jail participants:***

"Seeing a person who does have it...now that would make me think...I want the information from someone who has it..."

"...seeing someone who does have it is most effective...being around them and touching skin."

"...maybe some visual examples..."

***Two Eagle River School participants:***

"I think that's what you need, somebody that has it to speak out to people and tell them how it is, I think that would make young people think about it...people would take it more seriously."

"...a person who's actually infected from it, because then without a doubt I would really start thinking about it...after they told me everything...It's like, 'I'm cool, I can go with that.'"

"...because actually, why have somebody talk to you that don't have it? Somebody talk to you that does have it, that knows what's going on...then you'll know the facts...that would bring like more attention too because someone infected by it, they'll [kids] listen more about AIDS..."

"...just bring in that HIV infected woman, I met her like two times...it was a conference in Billings. A lot of people showed up..."

"...you just get scared more and care more...you're affected more..."

## **Condoms**

Condoms were a major theme across all four focus groups. Native American health educator participants felt it is important not only to provide Native youth with more HIV/AIDS information, but also to provide more education concerning proper condom utilization. Participants in this focus group made several references to condom use and the lack thereof. They expressed that many sexually active youth are unsure of proper and effective condom use. One participant remarked that some sexually active adolescents have little or no experience with condoms and condom application.

It was evident by Two Eagle River participant responses they were unsure regarding proper and effective condom use. A few Two Eagle River School participants relayed personal experiences with condoms breaking. Others felt “nobody ever does use condoms because they’re uncomfortable and they take the feeling away.” Other excuses for not using condoms included, too embarrassed to get them, “don’t feel like going to the store at 1:00 in the morning” to get them, and “don’t have one.” In terms of condom distribution, the students felt condoms should be available and distributed all the time, especially on Fridays.

It was apparent in the Tribal Jail focus group that many of the inmates have not been practicing safe sex. When asked about condoms, one older participant remarked that he has “never used them in the past and was not going to begin now.” Another commented on how many of his friends, many older individuals, “weren’t raised in the AIDS generation and don’t use condoms.” The group agreed they do not get the same feeling with a condom as without. Condoms and sensitivity, or the lack thereof, was also an issue. However, participants felt more condom distribution and condom information is

necessary in schools. Lastly, Indian Teacher/Parent Council participants felt that condoms should be distributed “in the right age group.” This group perceived middle school youth to “not be mature enough to handle that kind of stuff.” One participant believed many youth in this age group have not had enough HIV/AIDS education and therefore do not take condom distribution seriously.

***Native American health educator participant:***

“I know I’ve asked some of the young men if they’ve ever put a rubber on...or I talk to the girls and ask them if they know what a rubber feels like, and I get alot of giggles...but, you know, you can say, ‘Use a condom!’ all day long but unless they’re actually willing to touch the damn thing, you know, and play with it and see what it feels like and stuff, I mean, they’re not even gonna try...”

***Indian Teacher/Parent Council participant:***

“Condoms should be distributed within the right age group. I have had trouble...I’ve had to tell my young girls, which are almost seventh graders, to put them back because I knew they were going to end up on our playground just being thrown at kids and blown up like balloons. It just depends, I think we need to look at the population we’re serving and talk about it before we make them available. I know high school age this is different but our middle school age kids, they’re just not mature enough to handle that nor have we given them the right education on it yet. They’re not serious about it and they end up on our playground all over the place...”

***Tribal Jail participants:***

“I’m in my mid-thirties and alot of people my age wouldn’t bother using condoms, it’s like a stigma...I didn’t use them then, I ain’t gonna use them in the future...I wasn’t raised in the AIDS generation.”

“You can’t teach an old dog new tricks...I mean they’ve gotten this far without them...”

“I think that’s the main issue, you don’t get the same feeling.”

“Just give ‘em out, man. Just have ‘em out everywhere, everyday...”

***Two Eagle River School participants:***

“I don’t use them all the time because I don’t have them all the time. You never know when your gonna smack [have sex]...”

“...sometimes the condoms breaks too, you could be so far into it you wouldn’t care to put another one on, you just go for it, man...”

“About the condom thing, man, when your doing it with a condom on sometimes the condom might slide off and it might get stuck up there and stuff and sperm will still get out and stuff, or it might break. Even with the condom, man, you can still get AIDS...”

“That’s the whole problem, nobody ever does use condoms...”

“It’s easier if someone just gives them [condoms] out than to have to ask for them. They should give them out every weekend, every Friday, have them available at any time...”

“Some people’s excuse is they take the feeling away, they’re uncomfortable...”

## **Native youth**

With the exception of the Two Eagle River School participants, the remaining three focus groups placed tremendous emphasis on the importance of targeting Native youth in terms of HIV/AIDS information. However, it was evident throughout the Two Eagle River School focus group interview that Native youth need more attention regarding HIV/AIDS. Participants in this group had more questions and relayed many more experiences reflecting their confusion concerning HIV/AIDS information. Clearly, they have been misled and are frustrated with the continual circulation of HIV/AIDS misinformation. Repeatedly, these participants remarked on the need for more “hard,” fictional HIV/AIDS information as well as a heightened sense of HIV/AIDS awareness for their peers.

Furthermore, when participants in the remaining three focus groups were asked at the end of each interview if they had any additional comments, the overall message was more HIV/AIDS education and prevention information for Native youth. One Tribal Jail participant believed it was vital to “get to the young people.” Native American health

educator participants continuously referred to Native adolescents throughout the focus group interview. Indian Teacher/Parent Council participants also repeatedly referred to the Native young. In fact, at one point during the Teacher/Parent Council interview, the Native American facilitator reminded participants there would be a focus group involving young Two Eagle River students. She asked participants to please try and focus on issues regarding Native older adults.

***Indian Teacher/Parent Council participants:***

“I know you’re focusing on parents tonight...but one of the places to reach kids everyday is school...”

“...alot of the risk we as adults think about are risks we associate with our kids...”

***Indian Teacher/Parent Council Native American facilitator:***

“...I’m going to butt in here for a minute...we’re going to have a focus group at Two Eagle and we’re going to talk to eighteen-year-olds and we’re going to get issues regarding their age group. Tonight we kind of want to stay in your level, like adults...”

***Tribal Jail participants:***

“...get to the young people...”

## **Chapter V**

### **Discussion**

The purpose of this study was to assess the HIV prevention needs of Native Americans on the Flathead Indian Reservation in Montana. Subsequently, this information will be used to develop a social marketing campaign designed to increase perceptions of behavioral risk of HIV infection and decrease barriers to HIV counseling and testing among this population. This chapter includes contextualizing thematic results into a social marketing theoretical framework. In addition, limitations of the study and recommendation for further research are discussed.

### **Social Marketing**

Prior to developing a social marketing campaign, a number of steps are recommended to increase the likelihood of the campaign's success. Moreover, equal attention and consideration need to be given to each step in the development of a social marketing campaign. Bensley & Brookins-Fisher (1998) recommend application of the following steps when developing a social marketing campaign: 1) knowing the health issue, 2) researching the target audience, 3) identifying the best channel for marketing the message, 4) pilot testing with a smaller target audience, 5) fully implementing and continually refining the marketing strategy and, 6) utilizing public relations techniques. Following is a description of the first three steps that were the emphasis of this study.

### **Step 1: Identifying the health issue:**

The paramount health issue is HIV/AIDS infection among Native Americans on the Flathead Indian Reservation in Montana. Specifically, lack of HIV/AIDS knowledge and perceived no or low risk of HIV/AIDS infection among Native people on the reservation. A review of the literature (see Chapter II, p.12-21) was conducted by the researcher in order to gain a thorough understanding of the issue. A review of the literature revealed that HIV/AIDS is increasing significantly among various racial and ethnic groups (AAWH, 1997). LeMaster & Connell reported that among Native Americans, there is “an increase in the prevalence of diseases and conditions with a strong behavioral component as the leading cause of mortality and morbidity.” As of December 31, 1997, Montana has reported a cumulative total of 376 individuals diagnosed with AIDS as defined by the CDC (1997). Department of Public Health and Human Services (DPHHS) estimates that as many as 500 Montanans, including approximately 150 individuals living with an AIDS diagnosis, may be infected. 25 cases of AIDS has been reported to the DPHHS (1997) since 1985 in Montana’s Lake County alone. Furthermore, results from a study conducted at The University of Montana in 1997 concluded that Montana’s Native Americans believed themselves to be at “low or no risk” for contracting HIV/AIDS (Mochi, 1997).

In addition to a review of the literature, the researcher conducted focus groups with Native Americans on the Flathead Indian Reservation in order to gain a thorough understanding of the HIV/AIDS education and prevention needs of this population. In the process of interacting with and conducting focus group interviews with Native Americans to assess HIV/AIDS prevention needs, the researcher discovered health concerns related



to HIV/AIDS evident among this population. These HIV/AIDS related health concerns will provide additional insight into the HIV/AIDS education and prevention needs of Montana's Native Americans.

One of the most dominant problems among Native Americans on the Flathead Reservation is misinformation regarding HIV/AIDS. All focus group participants agreed the community had difficulty deciphering factual HIV/AIDS information from fictitious HIV/AIDS information. In addition, participants concluded many Native people in the community believe HIV/AIDS is nonexistent in Montana. In accordance with Mochi's (1997) findings, some focus group participants did not perceive themselves to be at risk for HIV/AIDS infection. Even more detrimental, and perhaps due to both the belief that HIV/AIDS is not in Montana and the perception they are not at risk for HIV/AIDS infection, many Natives reported engaging in risky behaviors, such as unsafe sex and intravenous drug use. Finally, the attitude of hopelessness and apathy regarding HIV/AIDS, both among participants and perceived by participants as permeating the community, was apparent throughout the focus groups involving the younger Natives (Two Eagle River School participants and Tribal Jail participants). This attitude of hopelessness and apathy in conjunction with HIV/AIDS misinformation, the belief that HIV/AIDS is not in Montana, perception of risk and willingness to engage in risky behaviors, are additional barriers to HIV/AIDS counseling and testing among Native Americans on the Flathead Indian Reservation. The identification of these HIV/AIDS related health concerns among this population will be beneficial in designing a social marketing campaign.

## **Step 2: Researching the target audience:**

Social marketing campaigns have several unique aspects that distinguish them from other health information and education programs. One essential aspect involves targeting specific segments of the population with shared characteristics, attitudes, values and behaviors. The purpose of targeting specific populations is to examine what influences and motivates behaviors among groups of people and then design strategies to affect those behaviors - to promote, change or maintain them. In other words, social marketing strategies must be tailored to each target segment in order to be truly effective.

Researching the target audience was accomplished via focus groups (see Chapter IV, p.28-62). The target audience included Native Americans over eighteen-years-of-age who reside on the Flathead Indian Reservation in Montana. Specifically, participants were individuals who engage in high-risk behavior and members of the community who have experience working with individuals who engage in high-risk behaviors. In social marketing, central to targeting specific segments of the population (Native Americans), is the premise that within this target audience there exists segments of the population that have distinct characteristics and values. Native Americans at risk and Native Americans who have contact with those at risk for HIV/AIDS were targeted.

Four focus groups were conducted. Focus group participants included Native American health educators, members of the Indian Teacher/Parent Council, inmates at the Tribal Jail, and students at the Two Eagle River School. The researcher chose these four groups to interview for a number of reasons. Health educators were interviewed because the researcher felt these individuals would be able to provide some insight into the state of existing HIV/AIDS education and prevention services on the reservation. This group

would be able to relay not only their feelings on the effectiveness and relevance of HIV/AIDS services on the reservation, but they would also be able to render their opinions on what the reservation is lacking in terms of HIV/AIDS education and prevention services. Moreover, their assistance in refining the focus group instrument and focus group procedures in order to elicit more detailed HIV/AIDS information from participants would be invaluable.

The next group, members of the Indian Parent/Teacher Council, was chosen for their perceptiveness regarding not only Native youth but high-risk Native youth as well. The researcher believed this group might also be able to provide some insight into what problems Native adults perceive as detrimental to the community regarding HIV/AIDS.

Inmates at the Tribal Jail were chosen because it is believed this group engages in risky behaviors, such as unsafe sex and intravenous drug use. The researcher thought the inmates might be able to relay some ideas and concerns of high-risk adults and of intravenous drug users. Also, it was believed this group could provide insight into the perceptions and experiences of intravenous drug users.

Finally, the Two Eagle River School is an alternative high school for troubled youth. Two Eagle River School students were chosen because it is believed these Native youth engage in high-risk behaviors or know other Native youth who engage in high risk behaviors. The researcher believed this group could provide some intuition into the perceptions and experiences of Native youth regarding HIV/AIDS.

### **Step 3: Identifying the best channels:**

Central to developing a social marketing plan is identifying the best channels for communicating the message to the target audience. Social marketing strategies must be tailored to each target segment in order to be truly effective. Therefore, recommendations for designing an HIV/AIDS social marketing campaign among Native Americans on the Flathead Indian Reservation will not target the entire Native community. Rather, recommendations will include strategies targeted specifically towards Native adults and strategies targeted specifically towards Native youth. In addition, recommendations are based on thematic results of focus group interviews.

### **Recommendations for HIV/AIDS education and prevention strategies**

#### **Native adults:**

There are several different strategies available to combat the problem of HIV/AIDS among Native American adults on the Flathead Indian Reservation. These strategies have the potential to not only heighten HIV/AIDS awareness among Native American adults on the reservation, but also increase perceptions of HIV/AIDS risk and decrease barriers to HIV/AIDS counseling and testing among this target audience.

#### **Captive audience approach**

To begin, adults in all focus groups perceived the most effective way to reach adults is through the “captive audience” approach. That is, incorporating HIV/AIDS facts/information into their daily lives, their daily routines. Short statements of HIV/AIDS information facts submitted into paychecks or placed onto the front of video poker

machines is one way to disperse the message to Natives as well as having HIV/AIDS facts/information available when Natives vote in elections, or register to vote. HIV/AIDS information could be disseminated with the purchase of hunting licenses or when Natives gather to receive buffalo meat. HIV/AIDS information pamphlets available at doctor's offices or in highly accessed areas at workplaces is another way to spread the message. Piggybacking the HIV/AIDS information onto something else, making it easier for Native people to receive HIV/AIDS information, was a theme imbedded within adult participant focus groups. This would be a beneficial and effective way to channel the HIV/AIDS messages.

### **HIV/AIDS workshops**

A second effectual channel to consider would be a series of weekly HIV/AIDS related workshops. Focus group participants agreed it would be essential to hold these workshops in a central location on the Flathead Reservation, and, perhaps, to seek sponsors who are willing to donate free food (pizza) and soda to entice Native participation. In addition, it is important to include culturally appropriate elements in these workshops, making them culturally specific, as well as culturally sensitive. Involving a Native American from the reservation to organize and synthesize the workshops would be critical.

These workshops could be fundamental in addressing several of the problems adult participants perceived as detrimental to the Native community. For instance, a series of eight workshops, possibly entitled "AIDS in Eight," held once a week for eight weeks, addressing the following prominent problems as perceived by Native adult focus group participants:

- Week 1: Fact from fiction: Learn the facts about HIV/AIDS
- Week 2: How to talk to your kids about HIV/AIDS
- Week 3: Community professionals HIV/AIDS information night
- Week 4: Singles HIV/AIDS education night
- Week 5: Teacher HIV/AIDS information night
- Week 6: HIV infected speaker night  
(and/or speakers who have worked with HIV/AIDS patients)
- Week 7: Risky behaviors...know the risks, learn how to protect yourself
- Week 8: Everything you ever wanted to know about HIV/AIDS but were afraid to ask!  
HIV/AIDS question and answer night  
\*Members of the community drop questions anonymously into boxes placed in highly accessed spots within the community. Questions are read and answered by health professionals.

Free HIV/AIDS testing as well as free condoms and free needle kits available at each workshop would be beneficial. A table displaying different sources of HIV/AIDS information, such as hotline numbers and internet addresses would also be helpful.

Compiling a list of resources including all of the different means to receive HIV/AIDS information and having this list available at each workshop would be instrumental in spreading the message. Furthermore, a display of graphic, visual examples of individuals with HIV/AIDS or a series of photographs depicting the physical changes involved with the debilitating effects of the disease would, as perceived by focus group participants, have a profound impact. If this was not possible, an HIV/AIDS movie which tells the story of an HIV/AIDS victim from the onset of the disease to his/her death would be effective as well.

## **HIV/AIDS information and testing at the Tribal Jail**

In addition to HIV/AIDS testing and information at these workshops, individuals who are detained at the Tribal Jail could also have access to HIV/AIDS information and testing, on site at the jail. Pamphlets could be disseminated to individuals upon their arrival at the Tribal Jail. Also, HIV/AIDS information and testing at DUI (driving under the influence of alcohol or drugs) classes would be advantageous.

## **Spreading HIV/AIDS facts**

Lastly, local radio stations could air PSA's (public service announcements) containing HIV/AIDS facts and information. Morning talk/radio shows could sponsor a "Question (or fact) of the day" regarding HIV/AIDS. Highly visible billboards in the community could display one fact pertaining to HIV/AIDS, possibly changing the fact every month or every other month. The fact could simply be the number of HIV/AIDS cases in Lake County or in Montana. Churches and other places of worship could also be accessed, encouraging HIV/AIDS related awareness events such as workshops.

In retrospect, mixing the message with part of Natives daily lives/routines and personalizing it, making the HIV/AIDS information or related event personal to Natives are vital in spreading the message about HIV/AIDS on the reservation. These two strategies are the most effective ways to increase HIV/AIDS perception of risk and decrease barriers to HIV/AIDS counseling and testing among Native adults.

## **Recommendations for HIV/AIDS education and prevention strategies**

### **Native youth:**

There are several different strategies available to combat the problem of HIV/AIDS among Native American youth on the Flathead Indian Reservation. These strategies have the potential to not only heighten HIV/AIDS awareness among Native American youth on the reservation, but also increase perceptions of HIV/AIDS risk and decrease barriers to HIV/AIDS counseling and testing among this target audience.

### **HIV/AIDS workshops**

To begin, the most dominant theme imbedded within the focus group involving Native youth was the problem of misinformation regarding HIV/AIDS. In addition, students stressed the importance of more HIV/AIDS education and awareness for youth. An effective channel to address this problem, as well as other problems youth participants perceived as detrimental to the Native community, would be a series of weekly HIV/AIDS related workshops. Focus group youth participants agreed it would be essential to hold these workshops at school, and, perhaps, to seek sponsors who are willing to donate free pizza and soda to entice Native youth participation. In addition, it is important these workshops be voluntary rather than mandatory. Involving Native youth in the planning and promoting of the workshops would also be critical. Workshops would be designed to address the problems youth participants face as well as those problems perceived by Native youth as detrimental to the Native community. For instance, a series of workshops similar to the ones recommended for adults, but targeted specifically at issues related to



Native youth and held once a week for eight weeks. If possible, these workshops could be held during the school day or after school for one hour or on a weekend night:

**Week 1: Fact from fiction: Learn the facts about HIV/AIDS**

**Week 2: How to talk to your boyfriend/girlfriend about sex and HIV/AIDS**

**Week 3: HIV infected speaker  
(and/or speakers who have worked with HIV/AIDS patients)**

**Week 4: Risky behaviors...know the risks, learn how to protect yourself**

**Week 5: Condom information and education...**  
**\*Including hands-on practice with their application and getting students more comfortable with their application.**

**Week 6: Just girls: HIV/AIDS discussion session exclusively for girls**

**Week 7: Just boys: HIV/AIDS discussion session exclusively for boys**

**Week 8: Everything you ever wanted to know about HIV/AIDS but were afraid to ask!**  
**HIV/AIDS question and answer session**  
**\*Students drop questions anonymously into boxes placed around school.**  
**Questions are read and answered by health professionals.**

Free HIV/AIDS testing and free condoms available at each workshop as well as a table displaying different sources of HIV/AIDS information, such as hotline numbers and internet addresses would be beneficial. Having this list of resources for HIV/AIDS information at each workshop would be helpful, but perhaps even more instrumental would be to have this list available everyday at school, not just on workshop days. This strategy may possibly address any confidentiality issues Native youth may have.

Furthermore, a display of graphic, visual examples of individuals with HIV/AIDS or a series of photographs depicting the physical changes involved with the debilitating effects of the disease would, as perceived by youth focus group participants, have a profound

impact. If this was not possible, an HIV/AIDS movie which tells the story of an HIV/AIDS victim from the onset of the disease to his/her death would be effective as well, especially if it involved an adolescent victim.

### **More condom distribution**

In regards to condom distribution, having them available at these workshops would be essential, but they should also be distributed everyday at school. Students felt condoms should be distributed everyday and if not everyday then at least every Friday. One student believed a condom campaign within school would be helpful: "Just wear it" or "Before you hump, cover your stump!"

### **Spreading HIV/AIDS facts**

Lastly, local radio stations, frequently listened to by Native youth, could air PSA's (public service announcements) containing HIV/AIDS facts and information. Morning radio shows could sponsor a "Question (or fact) of the day" regarding HIV/AIDS. Highly visible bulletin boards in school could display one fact pertaining to HIV/AIDS, possibly changing the fact every week or every other week. The same could be done in the bathrooms around school. The number of HIV/AIDS cases in Lake County or in Montana could be promoted and displayed around school. Churches, youth groups and other places worship could also be accessed, encouraging HIV/AIDS related awareness events such as workshops. Team sports and other groups associated with Native youth could be supplied with HIV/AIDS facts/information.

In retrospect, spreading the message among Native youth involves making the information relevant and unique to them. The most effective way to disseminate this information to Native youth would be through school. Students feel safe in school, they

are in a comfortable, familiar setting, surrounded by friends. Furthermore, many Native youth perceived adults as apathetic and uncaring. Youth learn by examples. If Native youth perceive Native adults as apathetic and uncaring about HIV/AIDS, they too will most likely adopt this attitude. To heighten the level of awareness among Native youth, it is imperative for Native adults to become more HIV/AIDS aware, acknowledging HIV/AIDS risk and utilizing the necessary preventative measures. More importantly, it is critical to encourage Native youth to do the same.

## **Limitations of the study**

It is reasonable to acknowledge that limitations exist within any study. Several limitations existed within this study that may or may not have impacted the quality of the data. This section discusses these limitations.

Focus groups were conducted by a Native American facilitator. Assisting with the facilitation were two Caucasian female facilitators (the researcher and her assistant). The presence of these non-Native Americans may have inhibited participant disclosure. In addition, the two Caucasian facilitators were introduced to the focus groups as “researchers.” Often times when individuals of a different cultural background conduct research involving Native Americans, the potential for mistrust is high among the Natives. Too often non-Native “researchers” conduct research “on” rather than “with” the Native community. Even more detrimental, many “researchers” have published their results without the blessing of the Tribal Council. These results have frequently contained stereotypical, generalized portrayals of Native Americans, often untrue and damaging to the Native reputation.

The Native American who organized the focus groups and assisted with the facilitation was well-known throughout the community. She was employed as a Native American Health Educator at the Tribal Public Health Department in St. Ignatius, Montana, which is part of the reservation. She knew many of the focus group interview participants and her presence may have inhibited participant disclosure.

Several minor distractions occurred during two of the four focus groups that may or may not have impacted the flow and discussion of the interview sessions. Throughout the Indian Parent/Teacher focus group interview, two small children were talking loudly and

playing rambunctiously amongst themselves. Periodically throughout the Two Eagle River School focus group interview, short announcements over the school intercom interrupted the discussion. Also, participants and focus group facilitators were forced to change rooms halfway through the Two Eagle River School interview due to a classroom scheduling conflict. Interestingly, the room change seemed to stimulate discussion and spark interest. Previous to the change, students were less talkative and appeared disinterested. Students were notably more comfortable and less apprehensive about speaking in the new room.

Present in each focus group interview were one or two participants who tended to dominate the discussion. These participants spoke repeatedly, often relaying personal experiences, stories and opinions. Selected quotes may reflect the opinions or attitude of the dominate speaker and not necessarily the opinions or attitudes of the entire group. Also, dominant speakers may or may not have intimidated other participants, discouraging them from voicing their opinions.

Among the Two Eagle River School focus group, there was one individual who not only dominated the discussion, but also contradicted himself a number of times, on a number of issues such as condom use and risk taking [of HIV transmission]. In addition, this dominant speaker was notably pessimistic. His entire attitude was one of hopelessness and despair. Clearly, he was extremely negative and untrusting of others, most especially adults. He perceived the Native community as very apathetic and uncaring regarding not only HIV/AIDS but also regarding the future and welfare of its Native youth. His dominance of the group may have discouraged other participants from responding.

Lastly, this study targeted four unique groups. All four groups were unique in their ages and consequently in their opinions, attitudes, beliefs and habits. One disadvantage to this is the researcher did not have the opportunity to examine themes from several different focus groups that targeted one particular age group. For example, the researcher was unable to examine reoccurring themes across four groups of Native youth. Rather, the perceptions of both Native youth and Native adults were examined. This was advantageous in that it allowed the researcher to gain a broad perspective of the perceptions of Native people of all ages.

### **Recommendations for further research**

The following section includes recommendations for researchers who plan to conduct research in the area of HIV/AIDS and Native Americans. These recommendations include:

- 1) One-on-one interviews would be beneficial to further pinpoint the HIV education and prevention needs of Native Americans.
- 2) Additional focus groups with each target audience would provide a greater sample of the Native American population. Therefore, results would be more representative.
- 3) Focus group questions would expand more on HIV/AIDS education and prevention strategies, eliciting more specific responses concerning HIV/AIDS issues.

## REFERENCES

Academy for Educational Development. (1995, May). Overview of HIV/AIDS Prevention Interventions: An Approach to Examining Their Effectiveness.

Allensworth, D., Gayle, J. & Kerr, D. (1991). School-Based HIV Prevention: A Multidisciplinary Approach. American School Health Association, p.1.

AAWH: American Association For World Health Resource Booklet (1997). Give Children Hope in a World with AIDS. Washington, D.C.

Anderson, Alan R. (1995). Marketing Social Change: Changing Behavior to Promote Health, Social Development, and the Environment. San Francisco, CA: Jossey-Bass Publishers.

Borg, W., Gall, J. & Gall, M. (1996). Educational Research: An Introduction. Longman Publishers, N.Y., p.194-200.

Centers for Disease Control (1995). HIV Counseling and Testing - United States, Morbidity and Mortality Weekly Report, 44.

Centers for Disease Control (1995). CDC Surveillance Summaries. Atlanta, GA.

Centers for Disease Control (1996). CDC Surveillance Summaries. Atlanta, GA.

Centers for Disease Control (1997). America Responds to AIDS: AIDS Prevention Guide. U.S. Department of Health & Human Services.

Denzin, N. & Lincoln, Y. (1994). Handbook of Qualitative Research. Thousand Oaks, CA: Sage.

Emery, E., Ritter-Randolph, G., Strozier, A., McDermott, R. (1993). Using focus group interviews to identify salient issues concerning college students' alcohol abuse. Journal of American College Health, 41, p.195-198.

Ferraroti, F. (1981). On the autonomy of the biographical method. In D. Bertaux (Ed.), Biography and society: the life history approach in the social sciences. Beverly Hills, CA: Sage.

Green, L.W. & Lewis, F. M. (1986). Measurement and Evaluation in Health Education and Health Promotion. Palo Alto, CA: Mayfield.

Harris, C. (1997) "Native Americans win \$100G to combat HIV/AIDS epidemic". Amsterdam News, vol. 88, Issue 25, p.16.

"HIV Capsule News Report: Reports of local policy responses to the AIDS/HIV epidemic." CDC's Prevention Marketing Initiative: A Multi-Level Approach to HIV Prevention.  
Issue 2, July 1994.

HIV Prevention & CSHE Project Newsletter (1994). Published by AAHE.  
Volume 2, Number 4.

Iowa Department of Health and Human Services (1997). Iowa Community Planning Group. STD/HIV Section.

Keller, K., Sliepcevich, E., Vitello, E., Lacey, Wright, W. R. (1987). Assessing beliefs about the needs of senior citizens using the focus group interview: A qualitative approach. Health Education Quarterly, 18, p.44-49.

Krueger, R. A. (1994). Focus Groups: A Practical Guide for Applied Research, Second Edition. Thousand Oaks, CA: Sage.

LeMaster, P.L., & Connell, C.M. (1994). Health Education Interventions Among Native Americans: A Review and Analysis. Health Education Quarterly, 21, p.521-538.

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic Inquiry. Beverly Hills, CA: Sage.

Missoula Indian Center (1997). Missoula, Montana.

Mochi, R. (1997). Barriers to Counseling and Testing for Three of Montana's High-Risk Populations. The Department of Health and Human Performance, University of Montana.

NASTAD: Social Marketing Update (1997, January). The Elements of Social Marketing. Volume 2, Issue 4.

Nix, H. L., & The Department of Sociology, University of Georgia. (1977). The Community and Its Involvement in the Study Planning Action Process. Atlanta: U.S. Department of Health, Education, and Welfare.

Ogden, L., Shepherd, M., Smith, A. (1996, February). The Prevention Marketing Initiative: Applying Prevention Marketing. The Academy of Educational Development and with Porter/Novelli.

Patton, M., (1987). How to Use Qualitative Methods in Evaluation. Newbury Park, CA: Sage Publications.



Rathus, S.A. & Bough, S. (1993). AIDS: What Every Student Needs to Know. Fort Worth, TX: Harcourt Brace Jovanovich College Publishers.

Reeves, T. (1996, March 25). Native American Women Takes Her Message on AIDS to her Community. Knight-Ridder/Tribune News Service.

Rubin, H. J. & Rubin, I. S. (1995). Qualitative interviewing: The art of hearing data. Thousand Oaks, CA: Sage.

Schochetman, G. & George, R., J. (Eds.). (1994). AIDS Testing: A Comprehensive Guide To Technical, Medical, Social, Legal, and Management Issues. New York, NY: Springer-Verlag.

Selik, R.M, Castro, K.G., & Pappaioanou, M. (1988). Racial/Ethnic Differences in the Risk of AIDS in the United States. American Journal of Public Health, 78, p.1539-1545.

Steckler, A. (1989). The use of qualitative evaluation methods to test internal validity. Evaluation and the Health Professions, 12, p.115-133.

Sowers, C. (1995, December 1). Indians With AIDS Turn To Tribal Healers Fighting New Curses With Old Methods. The Arizona Republic, p.A1.

Stewart & Shamdasani (1990). Focus Groups: Theory and Practice. Newbury Park, CA: Sage.

U.S. Department of Labor (1995). Indian Net Information Center: Washington, D.C.

# **Appendix A**

## **IRB Consent Form**

## **Informed Consent Form**

The purpose of this focus group is to gain an understanding of the uniqueness of HIV/AIDS issues in the Native American community. Our discussion will address anything you or other group participants bring up concerning HIV/AIDS. An interview guide will be used by a group facilitator to ask questions about HIV/AIDS such as "What needs to be done to prevent the spread of AIDS?", "Where would people go for help if they wanted information about AIDS?", "What kinds of things would motivate people to get tested for the AIDS virus?".

The focus group discussion will be audio-taped and should last no longer than one and a half hours. The statements you and others make will be kept completely confidential. After the focus group interviews are completed and the tapes are transcribed, it will be impossible to identify the source of any statements. When the project is completed, the audio-tapes will be erased. No person or persons will be identified by name in this project. Information gathered from this project will be made available to Montana's Tribal Health & Human Services and Montana's Department of Public Health and Human Services so they can better serve the people of the Native American community concerning HIV/AIDS issues.

Your participation in this study is voluntary and refusal to participate will involve no penalty. Also, at any time during the discussion please feel free to discontinue your participation for any reason. We are only seeking opinions and experiences that you feel comfortable talking about. Of course, when you do have something to say, honesty and accuracy are extremely important.

Risks of participation in this project may include: emotional distress or other psychological injury. Efforts will be made to make participants feel comfortable and no one will be forced to say or do anything against her or his will. Although the risks to the participants are minimal, a list of health services with contacts has been provided for your convenience. In the event you are injured as a result of this research, you should individually seek appropriate medical treatment. If injury is caused by negligence of the University or any of any of its employees, you may be entitled to reimbursement or compensation pursuant to the Comprehensive State Insurance Plan established by the Department of Administration under the

authority of M.C.A., Title 2, Chapter 9. In the event of a claim for such injury, further information may be obtained from the University's Claims Representative or University legal Counsel.

If you have any questions regarding this study, please feel free to contact Laura Dybdal at 243 - 6988, Annie Sondag at 243 - 5215, or Sandy Sorrell at 745-3525.

**I have read the above material and any questions I have were answered to my satisfaction. I am at least 18 years old and I agree to participate in this study, understanding that I may discontinue or withdraw at any time, for any reason.**

---

**Signature**

---

**Date**

---

**Witness**

---

**Date**

## **Appendix B**

### **Focus Group Questionnaire**

## **Focus Group Questionnaire**

- 1. What do you think needs to be done on the Flathead reservation to prevent the spread of AIDS?**
- 2. Where would people go for help if they wanted information about AIDS?**
- 3. Where would people go if they wanted to get tested for the AIDS virus?**
- 4. What kinds of things would motivate people to get tested for the AIDS virus?**
- 5. What does not work?**
- 6. Is there anything else we should know?**

## **Appendix C**

### **Revised Focus Group Questionnaire**

## **Focus Group Questionnaire**

Please tell us your name and where you live.

1. Think back to the last time you heard any information regarding HIV or AIDS. Where did you hear this information? (newspapers, magazines, TV, billboards, radio, friends, elders?)
2. Suppose a friend or family member came to you with questions about HIV/AIDS. Where would you send them?
3. What kind of information do people want/need about HIV/AIDS?
  - Prevention info or treatment info? or both?
  - What should the message be?
4. There are a lot of different ways to get the types of information you have just been talking about. How would you like to get this information?
5. Of all those ways of getting information, which do you feel is most important?
6. Suppose that a workshop on HIV/AIDS was held. Would you attend?
  - What would get you to attend?
7. In your opinion, what is working or most effective in terms of prevention?
  - What is not working?
  - Condom distribution?
8. At what age should we start educating?
9. We would like to help other Native Americans become more aware of AIDS. As we begin this project, what advice do you have for us?
10. Is there anything else we should have talked about but didn't?



## **Appendix D**

### **Demographic Information Sheet**

**Please check all answers that most accurately describe you:**

**Sex:** Male ☐ Female ☐

**Age:** ☐ Under 18  
☐ 18-24  
☐ 25-44  
☐ 45-65  
☐ Over 65

**Race/Ethnicity:** ☐ Native American  
☐ African-American  
☐ Asian/Pacific Islander  
☐ Hispanic Latino  
☐ Caucasian

**Annual Income:** ☐ Below \$10,000  
☐ \$10,000-\$15,000  
☐ \$15,001-\$25,000  
☐ Over \$25,000

**Are you:** ☐ divorced  
☐ married  
☐ never been married  
☐ living together  
☐ separated

**Do you have any children?** ☐ Yes  
☐ No

**If yes, how many?** ☐ **What ages?** \_\_\_\_\_

**Which town or city do you live in?** \_\_\_\_\_

**Are you a member of a tribe?** ☐ Yes  
☐ No

**If yes, which tribe?** \_\_\_\_\_

**Any other information you think is important for us to know:**

## **Appendix E**

### **Contact Summary Sheet (Focus Group Review Sheet)**

## **Focus Group Review Sheet**

Date \_\_\_\_\_ Group \_\_\_\_\_

1. How many men/women? Age? Physical description.

2. Mood/dispositions of individuals.

3. Thoughts/observations...

**4. Reoccurring themes/patterns...**

**5. Problems?**

**6. Direction or information needed for next group...**

## **Appendix F**

### **Demographic Information Indian Teacher/Parent Council**

## **Demographic Information for Indian Parent/Teacher Council**

According to the information participants voluntarily provided on the demographic information sheet, participants were as follows:

### **Age**

<b>18-24</b>	<b>1</b>
<b>25-44</b>	<b>9</b>
<b>45-65</b>	<b>4</b>

### **Annual Income:**

<b>Below \$10,000</b>	<b>2</b>
<b>\$15,001-\$25,000</b>	<b>1</b>
<b>Over \$25,000</b>	<b>11</b>

### **Children**

<b>Number with children:</b>	<b>12</b>
<b>Number without children:</b>	<b>2</b>

### **Race/Ethnicity:**

<b>Native American</b>	<b>9</b>
<b>Hispanic Latino</b>	<b>1</b>
<b>Caucasian</b>	<b>4</b>

### **Marital Status**

<b>Divorced</b>	<b>3</b>
<b>Married</b>	<b>9</b>
<b>Living together</b>	<b>2</b>

### **Tribal Members:**

<b>Yes</b>	<b>8</b>
<b>No</b>	<b>6</b>

**Appendix G**

**Demographic Information**  
**Tribal Jail Inmates**



## **Demographic Information for Tribal Jail Inmates**

According to the information the inmates voluntarily provided on the demographic information sheet, participants were as follows:

### **Age**

**18-24     3**

**25-44     4**

**45-65     2**

### **Annual Income:**

**Below \$10,000     7**

**\$10,000-\$15,000     2**

### **Children**

**Number with children:     7**

**Number without children: 2**

### **Race/Ethnicity:**

**Native American     8**

**African-American     1**

### **Marital Status**

**Married     2**

**Never been married     2**

**Living together     3**

**Separated     2**

### **Tribal Members:**

**Yes     9**

**No     0**